All Wales Endocrine Standards
for Children and Young People’s Specialised Healthcare Services
Foreword

It gives me great pleasure to introduce the latest in this series of documents which set out to address the specific needs of children and young people accessing specialised healthcare services in Wales, and will form the foundation for the establishment of managed clinical networks to deliver these services.

The development of this document is thanks to an enormous amount of work by clinicians, service providers, healthcare professionals, voluntary organisations, parents and our children and young people and I would like to express my thanks to all those involved.

The Welsh Assembly Government continues to believe that the best investment we can make in the future is ensuring high quality and equitable services are provided for our children and young people. These documents will build on the important improvements already underway following the publication of the Children’s National Service Framework in 2005 in delivering the best services for the children and young people of Wales.

Edwina Hart AM OSTJ MBE
Minister for Health and Social Services
Introduction to the Project

In 2002, the Specialised Health Service Commission for Wales undertook a review of specialised healthcare services for the children and young people of Wales, which identified that these services were delivered in an ad hoc and fragmented way. Following this review, the Minister for Health and Social Services announced that Managed Clinical Networks (MCNs) would be developed to deliver specialised healthcare services for children and young people.

The Children and Young People’s Specialised Services Project (CYPSSP) was established by the Welsh Assembly Government (WAG) 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:

- To develop service specific standards for specialised healthcare services for the children and young people of Wales
- To enable equity of access through effective managed clinical network models for all children and young people in Wales requiring specialised services.

The agreed specialised services for the project are:

- Paediatric Critical Care (previously published in 2003)
- Neonatal Services
- Paediatric Neurosciences
  - Neurosurgery
  - Neurology
  - Neurodisability
- Paediatric Oncology
- Paediatric Palliative Care
- Paediatric Anaesthesia and Surgery
  - Anaesthetics
  - General Surgery
  - Trauma and Orthopaedics
- Ear, Nose and Throat
- Ophthalmology
- Plastic Surgery
- Burns
- Maxillofacial
- Cleft Lip and Palate

- Paediatric Nephrology
- Paediatric Cardiology and Congenital Cardiac Services (and access to Cardiac Surgery)
- Paediatric Endocrinology
- Paediatric Gastroenterology, Hepatology and Nutrition
- Paediatric Inherited Metabolic Disease
- Paediatric Respiratory Disease

The Standards Documents

This document is one of a series of standards for specialised services for children and young people, which were issued for consultation between 2005 and 2009. The first 6 final documents were launched by the Minister for Health and Social Services on the 8th December 2008. These were the Universal Standards, Cardiac Standards, Respiratory Standards, Palliative Care Standards, Neonatal Standards and the Gastroenterology, Hepatology and Nutrition Standards documents.

The standards and key actions in this document are written from an all Wales perspective and therefore apply to all children and young people with this particular health need, wherever they live in Wales.\textsuperscript{4, 5, 6}

There is also a Universal Standards document which contains key actions (KAs) that apply to all specialised services for children and young people. This document was initially consulted on in 2005, however it has continued to evolve, as further “universal” key actions have been identified during the development of the service specific standards. The Universal Standards should be read and used in conjunction with each of the service specific standards documents.

The CYPSSP standards should also be read and used in conjunction with the National Service Framework for Children, Young People and Maternity Services in Wales (Children’s NSF)\textsuperscript{7} in particular Chapter 2, “Key actions universal to all children” which is relevant to all services and all children and young people.
The standards and key actions within the CYPSSP documents apply to all children and young people accessing the specific specialised service who are between the ages of 0-18 years of age. However, key actions that relate to transition apply to all young people who may require ongoing services beyond this age range. The age for transition to adult services must be flexible to ensure that all young people are treated by the most appropriate professional and in the most appropriate setting. This will depend on the young person's mental, emotional and physical development.

**Purpose of standards**

The standards and their key actions have been developed to provide a basis for service planners and providers to plan and deliver effective services. They are to be used to benchmark current services and inform the development of future services to meet the specialised health needs of children and young people across Wales.

**Developing the standards**

An External Working Group (EWG) representative of key stakeholders has developed the standards for each service. Membership details can be found in Appendix 1 of the service specific standards documents.

The contribution made by EWG members is greatly appreciated. We are particularly grateful to the children, young people and parents who have been involved in the development of this work.

The standards have been Quality Assured by a Project Steering Group comprised of strategic stakeholders, details of which are included as Appendix 2.

The standards have also been mapped against the Welsh Assembly Government’s Healthcare Standards. The Healthcare Standards for Wales set out the Welsh Assembly Government’s common framework of healthcare standards to support the NHS and partner organisations in providing effective, timely and quality services across all healthcare settings. There are 32 Healthcare Standards covering four domains; The Patient Experience, Clinical Outcomes, Healthcare Governance and Public Health. These are designed to deliver the improved levels of care and treatment the people of Wales have a right to reasonably expect. The standards will be taken into account by those providing healthcare, regardless of the setting. Examples of how the Healthcare Standards map across the CYPSSP standards are referenced at the end of each section.

The Healthcare Standards are used by Healthcare Inspectorate Wales (HIW) as part of their process for assessing the quality, safety and effectiveness of healthcare providers and commissioners across Wales.
Since the CYPSSP commenced in 2003, three project managers have successfully managed and facilitated the development of the standards documents. We would like to extend our grateful thanks to all of the Project Managers, namely Eiri Jones, Sian Thomas and Mary Francis for their contribution to this work.

Delivering the standards

Some of the key actions can be delivered within a year, however due to workforce and financial constraints others will take a number of years to achieve. Thus each key action has a timescale for delivery between one and ten years.

Every attempt has been made to ensure that the key actions are clear and measurable. However when terms that cannot be measured such as ‘timely’ and ‘appropriate’ have been used it will be for the specific MCN to agree on the acceptable definition of the term. This will allow each standard and key action to reflect the particular needs of each individual specialised service.

Whenever ‘children’ are referred to in this document it should be accepted that this also includes young people. Reference to ‘parents’ includes mothers, fathers, carers and other adults with responsibility for caring for the children.

Monitoring the standards

Standards will be monitored and audited annually as part of the MCN arrangements and will include audit of training, practice and compliance with pathways, protocols and agreed outcomes.

Managed Clinical Networks (MCNs)

Children and young people accessing specialised services in Wales inevitably experience different patterns of care depending on the geography and population characteristics that impact on service provision in their locality. However it is crucial that although the pattern of care provided may differ, the standard of care provided does not. Developing MCNs is a way of ensuring that all Welsh children and young people receive equitable and high quality specialised services wherever they live in Wales.

MCNs can be defined as:

“Linked groups of health professionals from primary, secondary and/or specialist care, working in a co-ordinated manner, unconstrained by existing organisational boundaries, to ensure equitable provision of high quality and clinically effective services.”15
Through the formal establishment of MCNs, children and young people in Wales requiring specialised healthcare will access services in accordance with 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.*

An MCN is comprised of a number of disciplines working together in a co-ordinated, non-hierarchical manner, unconstrained by professional and organisational boundaries. As a result of this collaborative mechanism, MCNs aim to facilitate and promote equitable, quality services through the provision of seamless care.

Many disciplines already work in an informal professional network. However this is not the case across all professions and health sectors. MCNs provide a co-ordinated and managed structure, integral to which are agreed protocols and pathways of care, clinical audit, training and continuing professional development.

It should be acknowledged that a child or young person might need to access more than one of the CYPSSP speciality services. The MCN framework and structures for each speciality should ensure flexibility to work together to meet the needs of the child and delivery of appropriate seamless care.
Dental Care

Dental care is a service that has not been addressed separately. It is important to recognise that oral healthcare is a significant consideration for all children and young people and because of their medical conditions, many of the children and young people requiring specialised healthcare services may:

- be at higher risk of oral disease and oral complications
- be at higher risk when treated for oral disease e.g. children with respiratory disorders requiring general anaesthetics and children who have had cardiac surgery
- have particular problems that make the management of their dental treatment difficult, e.g. there may be associated learning disabilities.

Prevention of oral and dental disease is therefore highly desirable for this group of children and thus preventative oral healthcare advice should be part of every child’s overall care plan so that families and carers are well informed as to the specific risks for each child. Specific oral assessment and care should also be available where appropriate.

To facilitate this it is essential that the dental team is considered an integral part of the multidisciplinary approach advocated throughout this project and there should be a named dentist with specialised skills and knowledge in the oral healthcare of children e.g. a specialist in paediatric dentistry linked to each large District General Hospital (DGH) to provide support and advice to the broader teams and ensure referral of children for appropriate healthcare.
Paediatric Endocrine Services for the Children and Young People of Wales

Paediatric endocrinology is concerned with the diagnosis and management of children and young people with hormonal disorders (including growth problems). Many specialist paediatricians also care for patients with diabetes mellitus, as unlike adult diabetes services, paediatric diabetes is never managed exclusively in primary care.

Diabetes can be managed in secondary care, as long as clinics have an appropriate caseload and contain trained medical, nursing, dietetic and psychology staff. As treatment and follow-up are life-long, planned transition to adult services (via joint and/or hand-over clinics) is necessary. Specialised services may be required for the following:

- Diabetes complications in childhood
- Type 2 or rare forms of diabetes (e.g. Maturity onset diabetes MODY)
- Diabetes associated with chronic disease e.g. cystic fibrosis or high dose steroid usage e.g. in the treatment of some cancers.\(^{17}\)

Paediatric endocrine care is delivered by professionals working in many different areas of child health services. Most common conditions are managed in a primary or secondary care setting. Some of the more complex and rare conditions need to be managed in conjunction with a specialised children’s endocrine service.

It is noted that a significant number of cases are variations of normal development and can be managed locally. In some cases local investigations may reveal more complex conditions requiring referral to specialist services.

Common Endocrine Disorders

Common endocrine disorders include the following, as defined by the Royal College of Paediatrics and Child Health;\(^ {18}\)

- Short and tall stature
- Delayed puberty in boys
- Obesity
- Variations in pubertal development in girls
- Hypothyroidism
- Idiopathic isolated growth hormone deficiency.\(^ {19}\)

A minority of these children may require further detailed investigation and the more complex or difficult cases will require the expertise of the specialised service.
Uncommon or Complex Endocrine Disorders

A number of rare or more complex conditions require specialised expertise and should be managed by, or in conjunction with an endocrinologist. Examples of these include:

- Adrenal disorders (including Congenital Adrenal Hyperplasia)
- Thyrotoxicosis
- Turner Syndrome
- Hypopituitarism
- Precocious puberty in boys
- Rare endocrine tumours
- Disorders of calcium and bone metabolism
- Hypoglycaemia (non-diabetes related)
- Disorders of sexual development
- Ambiguous genitalia
- Endocrine disorders associated with chronic disease
  - Growth and pubertal problems associated with chronic renal failure and inflammatory bowel disease
  - Care of endocrine problems in cancer survivors
  - Cystic fibrosis related diabetes.

Adult Endocrine

It is vital that close relationships exist between paediatric and adult endocrinology services to ensure successful collaboration and transition planning.

Clinical Biochemistry

It is recognised that close liaison with specialist clinical biochemistry is integral to paediatric endocrinology.

Many diseases involve more than one system and therefore there needs to be a significant interface with other specialised services, in particular:

- Cardiology
- Metabolic
- Dermatology
• Haematology
• Gastroenterology
• Neurology
• Nutrition and Dietetic Services
• Neonatal
• Critical Care
• Genetics
• Palliative Care
• Nephrology
• Paediatric Surgery
• Gynaecology
• Neurosurgery
• Oncology
• Respiratory
• Radiology
• CAMHS/Psychosocial Support

Therefore these standards may need to be used in conjunction with the relevant service standards document.

Key documents have been used to inform the development of these standards, including:

• Commissioning Tertiary and Specialised Services for Children and Young People (2004), Royal College of Paediatrics and Child Health, London

• Type 1 diabetes: diagnosis and Management of Type 1 Diabetes in Children and Young People, (2004) NICE

• Consensus Guidelines-Standards 5&6 Diabetes National Service Framework (May 2007), Welsh Assembly Government

• Obesity: the prevention, identification, assessment and management of overweight and obesity in adults and children, (2006), NICE.

Some children will need to access services identified as “supra-regional”. These are highly specialised endocrine services. Access to these services for the children of Wales will be through the identified lead centre.
Current Service Model

Shared care and informal networks in endocrine services are well established across secondary and tertiary services for the children and young people in Wales.

South and Mid Wales

Common Endocrine Disorders

Children and young people are seen at their local district general hospital (DGH) and referred on to the lead centre (University Hospital of Wales (UHW), Cardiff) if necessary. Children with diabetes are cared for within their own local services.

Uncommon or Complex Endocrine Disorders

Children and young people requiring specialised care for complex endocrine disorders are seen at their local DGH and/or at UHW. If seen locally, the lead centre clinicians support this care through outreach clinics; but at present other members of the MDT do not accompany them.

The lead centre also offers the following services:

- Telephone advice service - 24 hr telephone advice from the consultant in the lead centre.
- Access to specialised nurse advice is currently available three days a week during the hours of 9am-5pm.
- Transfer Clinic - this is a handover service for young people with endocrine disorders entering the adult services. This service currently only exists at the lead centre.
- Specialist clinics for young people with disorders of growth associated with renal and gastrointestinal disease, cancer, adolescent gynaecology, genetic disorders and metabolic bone disease are currently held in the lead centre.

North Wales

The North Wales lead centre at the Royal Liverpool Children's Hospital (RLCH) does not currently provide outreach to North Wales, though shared care arrangements exist between the lead centre and North Wales.

Common Endocrine Disorders

Children and young people are seen at their local DGH and referred on to the RLCH if necessary. Children with diabetes are looked after within their own local services.
Uncommon or Complex Endocrine Disorders

Children and young people requiring specialised care for complex endocrine disorders are seen at their local DGH and discussed with the lead centre clinicians. No outreach service is available and where appropriate patients attend the lead centre for diagnostic investigation. Once management is established children attend the lead centre on annual basis with review appointments at the DGH during the intervening period.

The lead centre also provides the following services:

- Telephone advice from the consultant in the lead centre is available 9am-5pm, Monday to Friday. An informal arrangement exists between the consultant endocrinologists who can be contacted by telephone at most other times.

- Specialist clinics for disorders of sexual development, gynaecological endocrinology, cancer, neuroendocrinology and inflammatory bowel disease are also held.

- There is a NCG funded service for patients with hyperinsulinaemia in collaboration with the endocrine services in the Royal Manchester Children’s Hospital.

At present there is no transitional care service for children in North Wales.

Proposed Service Model

- Continue current arrangements but with all elements of the service fully planned and resourced.

- Additional resources to allow outreach clinics to local hospitals in North Wales.

- Additional resources to facilitate and support development of telephone advice service.

- Properly resourced transition process available locally rather than just at lead centres. Model to be defined by MCN.
Standard 1: Access to Endocrine Services

**Rationale:** All children identified with an endocrine health need have access to high quality, evidence based care provided by appropriately trained multi-disciplinary teams.\(^ {22}\) Standard 1

**Key Actions:**

<table>
<thead>
<tr>
<th>Key Action</th>
<th>Responsible organisation</th>
<th>Timescales</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.1 All children and young people with diabetes have local access to a multidisciplinary children’s diabetes team.(^ {17})</td>
<td>Health Boards MCN</td>
<td>Less than 1 year</td>
</tr>
<tr>
<td>1.2 All children and young people with endocrine disorders have access to the DGH endocrine team. (Appendix 3)</td>
<td>Health Boards</td>
<td>1-3 years</td>
</tr>
<tr>
<td>1.3 Children with uncommon or complex endocrine disorders are managed in conjunction with a specialist paediatric endocrine team. (Appendix 3)</td>
<td>Health Boards Lead Centres</td>
<td>Less than 1 year</td>
</tr>
</tbody>
</table>
| 1.4 Plans are made for every child requiring review by a member of the specialist team in one of the following ways:  
  - immediate in-patient transfer to a lead centre  
  - outpatient/day case appointment at a lead centre  
  - outreach specialist clinic appointment at the local DGH. | Health Boards Lead Centres | 1-3 years        |
<p>| 1.5 Children, young people and their families referred to the endocrine service are made aware of the services available to them within the MCN. | Health Boards MCN        | 1-3 years        |</p>
<table>
<thead>
<tr>
<th>Key Action</th>
<th>Responsible organisation</th>
<th>Timescales</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.6 Shared care protocols are in place for children and young people in Wales requiring investigations, diagnosis and management of endocrine disorders.</td>
<td>Lead Centre&lt;br&gt;Health Boards&lt;br&gt;MCN</td>
<td>1-3 years</td>
</tr>
<tr>
<td>1.7 There are shared care protocols and care pathways in place to support all children and young people in Wales who may require immediate treatment in an emergency situation.</td>
<td>Health Boards&lt;br&gt;Lead Centres&lt;br&gt;MCN</td>
<td>1-3 years</td>
</tr>
<tr>
<td>1.8 Telephone access to specialist consultant paediatric endocrine advice is available for staff in secondary care, 24 hours a day.</td>
<td>Lead Centre&lt;br&gt;Health Boards</td>
<td>Less than 1 year</td>
</tr>
<tr>
<td>1.9 Children, young people, their families and health professionals have access to clear instructions and consultant/specialist nurse advice during routine working hours.</td>
<td>Health Boards</td>
<td>Less than 1 year</td>
</tr>
<tr>
<td>1.10 Children and young people who are under the care of the endocrine service, and their families have access, outside working hours, to advice from local on-call services.</td>
<td>Health Boards</td>
<td>Less than 1 year</td>
</tr>
<tr>
<td>1.11 A transition pathway is in place for all young people with endocrine disorders to transfer to adult services.</td>
<td>Lead Centres&lt;br&gt;Health Boards</td>
<td>1-3 years</td>
</tr>
<tr>
<td>1.12 Young people with an endocrine disorder have the opportunity to be seen by a local gynaecologist with an interest in adolescent endocrine problems.</td>
<td>Health Boards</td>
<td>4-10 years</td>
</tr>
<tr>
<td>Key Action</td>
<td>Responsible organisation</td>
<td>Timescales</td>
</tr>
<tr>
<td>---------------------------------------------------------------------------</td>
<td>--------------------------</td>
<td>------------------</td>
</tr>
<tr>
<td>1.13 Children and young people with endocrine disorders have the opportunity to be seen by specialised adolescent gynaecological services at the lead centre.</td>
<td>Lead Centres</td>
<td>Less than 1 year</td>
</tr>
<tr>
<td>1.14 Local and specialised endocrine teams have access to biochemistry services. (Appendix 4)</td>
<td>Lead Centres Health Boards</td>
<td>Less than 1 year</td>
</tr>
<tr>
<td>1.15 Children and young people with endocrine disorders have access to multi-disciplinary outreach services and clinics.</td>
<td>Lead Centres Health Boards</td>
<td>1-3 years</td>
</tr>
<tr>
<td>1.16 Access to • urgent MRI at lead/specialist centres (for non neurosurgical emergencies) is available and reported on within 24 hrs • non urgent MRI scans (including those under general anaesthetic) are available and reported on within 12 weeks at all lead and specialist centres • pelvic ultra-sound scanning is available and reported on within 12 weeks at all DGHs • radiology services to determine and report bone age is available whenever a child attends their hospital appointment • dual energy x-ray absorptiometry (DEXA) is available and reported on within 12 weeks at all lead and specialist centres.</td>
<td>Lead Centres Health Boards</td>
<td>Less than 1 year</td>
</tr>
</tbody>
</table>

Examples of some of the Healthcare Standards for Wales (HCS) that map across to the above standard are HCS 2, 3, 6, 11, 12, 24 and 28.
Standard 2: Resourcing and Facilities for Endocrine Services

**Rationale:** Endocrine services are staffed with appropriately trained, multi-disciplinary professionals. Services are fully equipped to deliver appropriate and equitable care across the network in a child friendly environment with suitable faculties and equipment for their age and developmental needs. 

### Key Actions

<table>
<thead>
<tr>
<th>Key Action</th>
<th>Responsible organisation</th>
<th>Timescales</th>
</tr>
</thead>
<tbody>
<tr>
<td>2.1 A fully resourced multi-disciplinary team exists in the lead centre with the capacity to outreach. (Appendix 3)</td>
<td>Lead Centres</td>
<td>1-3 years</td>
</tr>
<tr>
<td>2.2 A DGH local multi-disciplinary team is resourced to provide the local element of specialised endocrine care in partnership with the lead centre. (Appendix 3)</td>
<td>Health Boards Lead Centre</td>
<td>1-3 years</td>
</tr>
<tr>
<td>2.3 Paediatricians with an interest in endocrinology/diabetes (Appendix 4) have a minimum of 2 sessions per week committed to the endocrine MCN.</td>
<td>Health Boards</td>
<td>4-10 years</td>
</tr>
<tr>
<td>2.4 Facilities are available in the lead centre/DGH to provide biochemical investigations. (Appendix 4)</td>
<td>Health Boards Lead Centres</td>
<td>Less than 1 year</td>
</tr>
<tr>
<td>2.5 Facilities are available in lead centres/DGH to provide radiological investigations and expert interpretation.</td>
<td>Health Boards Lead Centres</td>
<td>1-3 years</td>
</tr>
<tr>
<td>2.6 Facilities for day case investigations for children with endocrine disorders are available.</td>
<td>Health Boards MCN</td>
<td>1-3 years</td>
</tr>
<tr>
<td>Key Action</td>
<td>Responsible organisation</td>
<td>Timescales</td>
</tr>
<tr>
<td>---------------------------------------------------------------------------</td>
<td>--------------------------</td>
<td>------------------</td>
</tr>
<tr>
<td>2.7 There are shared care protocols for children and young people requiring treatment with specialist endocrine drugs.</td>
<td>Health Boards MCN</td>
<td>Less than 1 year</td>
</tr>
<tr>
<td>2.8 All children and young people requiring treatment with specialist endocrine drugs are funded/supported by shared care protocols.</td>
<td>Health Boards</td>
<td>Less than 1 year</td>
</tr>
</tbody>
</table>

Examples of some of the Healthcare Standards for Wales (HCS) that map across to the above standard are HCS 1, 2, 4, 11, 12, 19 and 24.
Standard 3: Care of the Child and Family

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

**Key Actions:**

All key actions are in the Universal Standards document.

Examples of some of the Healthcare Standards for Wales (HCS) that map across to the above standard are HCS 2, 4, 6, 8, 12 and 24.
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 Action:**

All key actions are in the Universal Standards document.\(^{22}\)

Examples of some of the Healthcare Standards for Wales (HCS) that map across to the above standard are HCS 1, 12 and 25.
Standard 5: Clinical Governance, Education and Training

**Rationale:** Endocrine services are staffed with appropriate multi-disciplinary professionals who are fully trained and supported to maintain their continuing professional development.²² Standard 5

**Key Actions:**

<table>
<thead>
<tr>
<th>Key Action</th>
<th>Responsible organisation</th>
<th>Timescales</th>
</tr>
</thead>
<tbody>
<tr>
<td>5.1 All paediatricians responsible for endocrine service delivery have undertaken specialist endocrine training to an appropriate level.²³</td>
<td>Health Boards</td>
<td>4-10 years</td>
</tr>
<tr>
<td>5.2 Lead centres are accredited training centres.²³ (Appendix 3)</td>
<td>Lead Centres</td>
<td>Less than 1 year</td>
</tr>
</tbody>
</table>

Examples of some of the Healthcare Standards for Wales (HCS) that map across to the above standard are HCS 11, 22 and 28b.
**Glossary**

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

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>CAMHS</td>
<td>Child and Adolescent Mental Health Service</td>
</tr>
<tr>
<td>Child Friendly Environment</td>
<td>An environment that is child safe and suitable for the age and development of the child with appropriate facilities for play</td>
</tr>
<tr>
<td>Health Boards</td>
<td>Providers of children’s healthcare services</td>
</tr>
<tr>
<td>Lead Centres</td>
<td>Health Boards delivering specialised services</td>
</tr>
<tr>
<td>NCG</td>
<td>National Commissioning Group</td>
</tr>
<tr>
<td>Play Specialists</td>
<td>Use play to support child’s assimilation and understanding of information, hospital environment, investigations and procedures</td>
</tr>
<tr>
<td>Shared Care</td>
<td>Varying components of care for the individual child or young person may be provided by different services and across organisational boundaries. Shared care may include that provided by families and carers as well as those of primary, secondary and tertiary care services</td>
</tr>
<tr>
<td>Supra-Regional</td>
<td>A specialist centre providing highly specialised services on a U.K wide basis</td>
</tr>
<tr>
<td>WHSSC</td>
<td>Welsh Health Specialised Service’s Committee</td>
</tr>
</tbody>
</table>
### Appendix 1

**Endocrine External Working Group Members (at time of consultation)**

<table>
<thead>
<tr>
<th>Name</th>
<th>Position</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dr John Barton (Chair)</td>
<td>Paediatric Consultant, Gwent Healthcare NHS Trust</td>
</tr>
<tr>
<td>Andrew Ferguson</td>
<td>Specialist Commissioner, Health Commission Wales</td>
</tr>
<tr>
<td>Dr Jo Blair</td>
<td>Consultant Paediatric Endocrinologist, Royal Liverpool Children's Hospital</td>
</tr>
<tr>
<td>Peter Laing</td>
<td>Clinical Nurse Specialist Endocrinology, Royal Liverpool Children's Hospital</td>
</tr>
<tr>
<td>Dr Gustav vas Falcao</td>
<td>Consultant Paediatrician, Pembrokeshire and Derwen NHS Trust</td>
</tr>
<tr>
<td>Dr Michael J Cronin</td>
<td>Consultant Paediatrician, North West Wales NHS Trust</td>
</tr>
<tr>
<td>Dr Peter Stutchfield</td>
<td>Consultant Paediatrician, Conwy and Denbighshire NHS Trust</td>
</tr>
<tr>
<td>Dr Lionel Jacobson</td>
<td>Honorary Lecturer, Cardiff University</td>
</tr>
<tr>
<td>Carol Evans</td>
<td>Clinical Biochemist, Cardiff and Vale NHS Trust</td>
</tr>
<tr>
<td>Dr Aled Rees</td>
<td>Adult Endocrinologist, Cardiff and Vale NHS Trust</td>
</tr>
<tr>
<td>Dr Dewi Evans</td>
<td>Consultant Paediatrician, Swansea NHS Trust</td>
</tr>
<tr>
<td>Catherine Bailey</td>
<td>Clinical Biochemist, Gwent Healthcare NHS Trust</td>
</tr>
<tr>
<td>Carol Fraser</td>
<td>Specialist Nurse, Swansea NHS Trust</td>
</tr>
<tr>
<td>Carol Percival</td>
<td>Specialist Nurse, Cardiff and Vale NHS Trust</td>
</tr>
<tr>
<td>Dr Justin Warner</td>
<td>Consultant Paediatric Endocrinologist, Cardiff and Vale NHS Trust</td>
</tr>
<tr>
<td>Mrs Maguire</td>
<td>Parent</td>
</tr>
<tr>
<td>Dr Huw Jenkins</td>
<td>Director of Healthcare Services for Children and Young People, Welsh Assembly Government</td>
</tr>
</tbody>
</table>
Appendix 2

Project Steering Group Members (as at time of consultation)

Chairs of the EWG’s

Gareth Jones (Observer)  Children Commissioner’s Office
Dr Gill Richardson  National Public Health Service
Alison Lagier  Local Health Board Chief Executives
Becky Healey  Welsh Nursing & Midwifery Committee
Angela Hillier  Welsh Therapies Advisory Committee
Zoe Goodacre  Health Commission Wales
Andrea Mathews  Wales Board of Community Health Councils
Dr Michael Badminton  Welsh Scientific Advisory Committee
Sue Greening  Welsh Dental Committee
Tom Woods  All Wales Trust Chief Executives
Caroline Crimp  Association for the Welfare of Children in Hospital
Keith Bowen  Contact a Family
Dr Huw Jenkins  Director of Healthcare Services for Children and Young People, Welsh Assembly Government
Appendix 3

Lead Centre Specialist Paediatric Endocrine Team\textsuperscript{21}
- Paediatric Endocrine Consultant (1 per 500,000 population)\textsuperscript{21}
- Specialist Registrar in Endocrinology
- Specialist Paediatric Nurses
- Specialist Paediatric Dietitians
- Psychologist
- Administrative Support
- Geneticist
- Data Clerk
- Access to a Paediatric Pharmacist
- Clinical Biochemist
- Paediatric Surgeon
- Adult Endocrinologist
- Adult Diabetologist
- Adolescent Gynaecologist

District General Hospital Paediatric Endocrine Team
- Paediatrician with an interest/link paediatrician\textsuperscript{21}
- Specialist Paediatric Dietitian
- Specialist Paediatric Nurse
- Psychologist
- Access to Clinical Biochemist
- Access to local adult Endocrinologist
- Access to local Diabetologist
- Access to Geneticist
- Access to all other tertiary Paediatric services
- Access to a Paediatric Pharmacist
- Access to Podiatry services
Specialised Clinical Biochemistry (Appendix 4)

- Peptide hormone services
- Steroid services

Definition of a Training Centre

A training centre can be a single institution or a group of related establishments accredited for training purposes by the British Society for Paediatric Endocrinology and Diabetes (BSPED).

Full Training Centre

The centre must provide adequate experience in all fields of endocrinology including emergency care. A full component of the secondary and tertiary courses must be provided. The number of activities must be sufficient to provide at least a minimum experience for a trainee. A group of related establishments can be considered a centre and each component considered as a unit contributing one or more modules to either the secondary or tertiary course.

The centre must have easy access and close relationships with other relevant specialties such as nuclear medicine, imaging facilities, surgery and laboratory facilities. The centre must provide evidence of ongoing clinical research and access to basic research.

The centre will be responsible for weekly clinical staff/seminar teaching and participation in regional/national meetings. Basic textbooks in endocrinology/diabetes should be immediately available and there should be access to a comprehensive reference library either in paper or electronic format.

Training Unit

Training units are institutions that provide training in one or more aspects of the secondary and/or tertiary courses. They must provide adequate exposure in the defined area and a teacher who is deemed competent in these areas.
Appendix 4

Standards relating to clinical biochemistry

All centres where children are admitted should have access to 24 hour, 7 days a week standard ‘routine’ biochemistry services. Routine endocrine biochemistry services should be available Mon-Fri 9am - 5pm. These services should also be available by arrangement outside normal working hours when urgently required. There should be access to 24 hour, 7 days a week advice from clinical biochemists or chemical pathologists.

Laboratories should be accredited by an appropriate body e.g. Clinical Pathology Accreditation (UK) Ltd (CPA). Laboratories should participate in appropriate external quality assurance (EQA) schemes for each analyte offered.

It may not be possible to offer specialist peptide hormone and steroid hormone services in DGHs. There should be access to comprehensive high quality specialist peptide and steroid hormone assays and expert advice Mon-Fri 9am - 5pm at a specialist centre. Specialist services should also be available by arrangement outside these hours when urgently required.

Resources should be available for referral of samples for specialist peptide and steroid hormone services as required.

Provision of specialist laboratory services requires:

- Experienced personnel trained to MRCPath standard to provide specialist interpretative advice.
- Qualified biomedical scientists registered with health professions council who are experienced in the techniques employed with appropriate scientific supervision to perform specialist assays.
- A programme of training in specialist services for biomedical scientists, clinical biochemists and chemical pathologists.
- Specialist centres should be equipped with the required technology to provide a quality analytical service.
- Development of services as appropriate to clinical requirements.
- A programme of multidisciplinary clinical audit to maintain the quality of services.
- A programme of sample exchange with other laboratories offering specialist services if EQAs are not available.
Sections 76, 77 and 81 of the Government of Wales Act 2006 provide a basis for our equality work. The National Assembly for Wales is under statutory duties to aim to ensure that its business is conducted, and its functions exercised, with due regard to the principle that there should be equality of opportunity for all people. As the majority of the National Assembly’s functions have been delegated to the First Minister and are carried out by the Welsh Assembly Government, in practical terms it is the Welsh Assembly Government which has principal responsibility for fulfilling these equality duties. This is further underpinned by UK Equality legislation, covering equality and human rights.
References


2. Specialised Health Service Commission for Wales (June 2002) A Special Service: The future of specialised healthcare for the children of Wales, Pontyclun: SHSCW.


18. Royal College of Paediatrics and Child Health, Commissioning Tertiary and Specialised Services for Children and Young People (2004), London: RCPCH.


