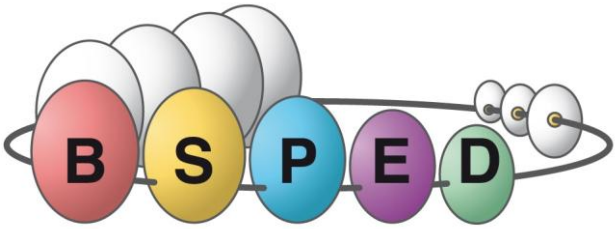

UK STANDARDS FOR PAEDIATRIC ENDOCRINOLOGY

2010

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1 PURPOSE OF STANDARDS

The endocrine standards and their key actions will provide a framework for service commissioners and providers to plan and deliver effective services for Paediatric Endocrinology. It can be used to benchmark current services and develop quality indicators which will allow robust monitoring of specialised endocrine services across the U.K. These standards have been developed by the Clinical Committee of the British Society for Paediatric Endocrinology and Diabetes (BSPED) and have taken into account Endocrine standards that have been published as part of the Children's and Young Persons Specialist Services Project (CYPSSP) in Wales[1] and proposed standards for Scotland. Five standards cover all areas of Paediatric Endocrinology:

- Standard 1: Access to specialised paediatric endocrine services
- Standard 2: Resources of specialised paediatric endocrine services
- Standard 3: Environment and facilities care of the child and family/patient experience.
- Standard 4: Communication
- Standard 5: Clinical governance, professional education and training, and evidence base.

For each standard evidence and/or guidance has been cited but this list is by no mean exhaustive and there are many other published policy documents which provide equally as valuable evidence for the standard.

2 PAEDIATRIC ENDOCRINE SERVICES

Paediatric endocrinology is concerned with the diagnosis and management of children and young people with hormonal disorders (including growth problems) and is considered to be a specialised service[2].

This document is concerned with standards relating to paediatric endocrine disorders and paediatric diabetes is not covered although many of the standards will be similar.

Paediatric endocrine care is delivered by professionals working in many different areas of child health services. Most common conditions are managed in a secondary care setting or in conjunction with primary care. More complex and rare conditions need to be managed solely or in conjunction with a specialised children's endocrine service through managed clinical networks (MCN) at regional level. A Managed Clinical Network is a network of a variety of health staff (including doctors, pharmacists, nurses, health visitors, physiotherapists and occupational therapists) and organisations from primary, secondary and regional health care working together to make sure that high quality clinically effective services are fairly distributed.

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 or conversely secondary care or parents may request a second opinion from tertiary care to confirm a non-specialist endocrine diagnosis which subsequently can be managed in secondary care.

Below is a model for managing relatively common endocrine disorders and those deemed to be more complex:

Level 1: Conditions with a low level of anticipated need for input from a paediatrician with an interest in endocrinology - managed in most cases by local general paediatricians:

- Familial short and tall stature children
- Nutritional obesity

Level 2: Conditions with a need for input from a paediatrician with an interest in endocrinology usually managed at local DGH clinics with occasional input from a paediatric endocrinologist at regional level on a shared care basis with the local teams. For some conditions the initial diagnostic investigations may need to be undertaken at the lead centre.

- Above conditions
- Primary hypothyroidism (congenital and acquired)
- Delayed puberty in boys
- Variations of early pubertal development in girls
- Vitamin D deficiency

Level 3: Conditions which require all or some management from a paediatric endocrinologist at regional level. These conditions are managed solely by a regional unit or through a network of endocrine clinics at the DGH, performed in combination by a regional paediatric endocrinologist and a local paediatrician with an interest in endocrinology. Some conditions that require MDT input from a number of specialists through joint clinics at regional or supra-regional level will require attendance at specialist centres for some of their visits.

- Anterior and Posterior Pituitary hormone deficiency
- Complex midline defects e.g. Septo Optic Dysplasia
- Early puberty in boys
- Delayed puberty in girls
- Gonadotrophin independent causes of early puberty
- Hyperthyroidism
- Complex genetic disorders e.g. severe insulin resistance, McCune-Albright syndrome, gonadotrophin-independent precocious puberty

- Endocrine abnormalities associated with chromosomal disorders e.g. Turner syndrome, Klinefelter syndrome, Prader Willi syndrome.
- Disorders of the adrenal gland including CAH, adrenal hypoplasia, ALD and Addison's disease
- Cushing's syndrome
- Obesity associated with co-morbidities
- Congenital hyperinsulinism
- Recurrent hypoglycaemia
- Disorders of calcium and phosphate metabolism
- Primary and secondary disorders of bone mass
- Skeletal dysplasias
- Endocrine tumours including familial forms
- Disorders of sex development
- Autoimmune polyglandular endocrinopathies
- Endocrine Disorders Associated with Chronic Disease
    - Growth and pubertal problems associated with chronic renal failure
    - Care of endocrine problems in cancer survivors
    - Cystic fibrosis related diabetes
    - Haematological disorders e.g. thalassaemia
    - Inflammatory conditions such as inflammatory bowel disease, arthropathies and other connective tissue disorders
    - Anorexia Nervosa
- Planning of transition to adult services

3 Adult Endocrine Service

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

4 Clinical Biochemistry

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

5 Access to other specialised services

It is also recognised that many diseases involve more than one system. There needs to be a significant interface with other specialised services, in particular[3]:

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

Some children will need to access services identified as "supra-regional". These are highly specialised Endocrine services. Access to these services will usually be through the regional lead centre.

Standard 1: Access to Specialised Paediatric Endocrine Services

Rationale: All children identified with an Endocrine health disorder need to have access to high quality, evidence based care provided by suitably trained multi-disciplinary teams.

Standard	Evidence and/or guidance	Metric	Measurement method
1.1 All children and young people with endocrine disorders have access to the local DGH endocrine team (level 1 and 2). *(*Appendix 1*)*	National Service Framework for Children, Young People and Maternity Services 2004[4] Modelling the future I A consultation paper on the future of children's health services 2007[5] Modelling the Future II Reconfiguration and workforce estimates 2008[6] Modelling the Future III Safe and sustainable integrated health services for infants, children and young people 2009[7]	Service is compliant with NSF guidelines Adherence to any published disease specific guideline e.g. congenital hypothyroidism[8] Job planning Waiting list times for OPA, day case investigation, inpatient investigation Referral times Evidence of shared care protocols	Quality review of patient notes Audit of individual diseases e.g. time to commence thyroxine in congenital hypothyroidism Evidence of defined clinical pathways and local guidelines Annual appraisal of job plan with appropriate time allowed for service delivery Compliance with local waiting list/referral times
1.2 Children with uncommon or complex endocrine disorders are managed in conjunction with a specialist paediatric endocrine team at the lead centre (all levels). (Appendix 1)			
1.3 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.			
1.4 Children, young people and their families referred to the endocrine service are made aware of the services available to them within the MCN.			
1.5 Shared care protocols are in place for children and young people requiring investigations, diagnosis and management of endocrine disorders.			
1.6 There are shared care protocols and care pathways in place to support all children and young people who may require immediate treatment in an emergency situation.			
1.7 Telephone access to specialist consultant paediatric endocrine advice (in the lead centre) is available for staff in secondary care, 24 hours a day.	Modelling the Future III Safe and sustainable integrated health services for infants, children and young people 2009[7]	On call rota Complaints about service	Availability of on call rota Patient satisfaction survey Audit of emergency admissions of children and young people with endocrine disorders
1.8 Children, young people, their families and health professionals have access to clear instructions and consultant/ specialist nurse advice during routine working hours.			
1.9 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.			

1.10 A transition pathway is in place for all young people with endocrine disorders to transfer to adult services.	Transition: getting it right for young people Improving the transition of young people with long term conditions from children's to adult health services 2006 [9]	Any patient in transition from paediatric to adult care should have a defined and agreed plan for handover of care. Transition clinics	Rapid quality review of patients' notes Patient satisfaction survey

1.11 Young people with a gynaecological endocrine disorder have the opportunity to be seen by a gynaecologist with an interest in adolescent gynaecology.	Consensus	Availability of specialist gynaecological services for children and young people	Rapid quality review of patients' notes
1.12 Children and young people with endocrine disorders have the opportunity to be seen by specialised adolescent gynaecological services at the lead centre.			

1.13 Local and specialised endocrine teams have access to Biochemistry services. (Appendix 2)	Consensus	Availability of routine and complex endocrine biochemical investigations	Audit of available investigations at the local and lead centre.
1.14 Children and young people with endocrine disorders have access to multi-disciplinary outreach services and clinics.	National Service Framework for Children, Young People and Maternity Services 2004[4]	Evidence of MDT	Availability of MDT

1.15 Access to: • urgent MRI at lead/specialist centres (for non neurosurgical emergencies) is available and reported on by a paediatric radiologist within 24 hrs • non urgent MRI scans (including those under general anaesthetic) are available and reported on by a paediatric radiologist within 12 weeks at all lead and specialist centres • pelvic ultra-sound scanning is available and reported on by a paediatric radiologist within 12 weeks at all DGH's with link to the lead/specialist centre for complex cases. • radiology services to determine and report bone age is available whenever a child attends their hospital appointment. • isotope scanning is available at lead/specialist centres • dual energy x-ray absorptiometry (DXA) is undertaken in centres with expertise in bone densitometry in children, scans are reported on within 12 weeks at all lead and specialist centres and a lead clinician is identified to link with medical physics for DXA.	Consensus A practical guide to bone densitometry in children, National Osteoporosis Society, November 2004[10]	Number of patients receiving investigation within the time frame Time taken from investigation to reporting.	Notes audit.

Standard 2: Resources of Specialised Paediatric Endocrine Services

Rationale: Paediatric endocrine services are adequately staffed with appropriate multi-disciplinary professionals who are fully equipped to deliver equitable care across the network. These staff are supported by other essential resources to deliver this care safely and effectively. In particular there is a need for access to inpatient beds at the lead centre for management of complex patients, a need for a day case investigation unit at lead centre and a need for co-location of the lead centre with other paediatric specialities e.g. paediatric neurosurgery, paediatric oncology etc.

Standard	Evidence and/or guidance	Metric	Measurement method
2.1 A fully resourced multi-disciplinary team exists in the lead centre with a capacity to outreach. (Appendix 1)	Modelling the Future II Reconfiguration and workforce estimates 2008[6]	A multi-disciplinary team outlined in Appendix 1 is available	Manpower surevey
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 1)	Consensus	Job plan	Local and regional Audit Analysis of job plan against workload
2.3 Paediatricians with an interest in endocrinology/ diabetes (Appendix 1) have defined sessions built in to their job plan committed to the endocrine regional network.			
2.4 The lead centre has co location with other specialist services detailed above in section 5	Commissioning Safe and Sustainable Specialised Paediatric Services – A framework of Critical Inter-Dependencies 2008[3]	Service is collocated with other specialised services as outlined in the Critical Inter-Dependencies document[3]	Audit of referrals out of the lead centre due to non availability of other specialist services Patient satisfaction survey
2.5 Facilities are available in the lead centre/ DGH to provide biochemical investigations. (Appendix 2)	Consensus	Biochemistry assay facilities as outlined in Appendix 2 are available for routine and complex endocrine investigations	Audit of available investigations at the local and lead centre.
2.6 Facilities are available in lead centres/DGH to provide radiological investigations and expert interpretation. (see 1.15)	See 1.15	See 1.15	See 1.15
2.7 There are shared care protocols for children and young people requiring treatment with specialist endocrine drugs.	Consensus	Shared care protocols are used for specialist drugs and are in keeping with approved BSPED/ESPE guidance	Comparison of local protocols to BSPED/ESPE approved protocols
2.8 All children and young people requiring treatment with specialist endocrine drugs are funded / supported by shared care protocols.	Growth failure in children NICE review[11] BSPED shared cared protocols[12]	Funding is in keeping with NICE guidelines where available Use of BSPED approved shared care protocols	Local audit against NICE guidance Evidence of shared care protocols
2.9 There are allocated IT and administrative services to enable rapid transmission of clinical information across the network.	Consensus	Hospital IT systems with intranet and internet access Patient database	Audit of letter times to referring HCP and/or information to parents
2.10 Workforce planning	Modelling the Future III	Success rate for business	Service expansion

mechanisms are in place to allow for year on year growth and service development dependent on a local needs assessment. 2.11 All Trusts guarantee continuity of the multidisciplinary team with timely succession planning. 2.12 In all units providing care for children and young people with endocrine disorders, staffing is planned to allow for: • study time • attendance at MDT meetings • CPD • Annual leave • Maternity leave • sickness 2.13 In all units, administrative support is provided to the MCN.	Safe and sustainable integrated health services for infants, children and young people 2009[7]	plans for service development Service activity Study leave allocation Annual leave allocation	 Monitoring of service activity to justify expansion and/or continuity and succession planning Annual appraisal and CPD certification See also 2.8
2.14 In all areas involved in the care of children and young people with endocrine disorders there is appropriate access to nurses trained in the care of children.	RCN Competencies: an integrated career and competency framework for paediatric endocrine nurse specialists 2008[13]	Compliance with the RCN competency framework	Review of nurses job plan to ensure adequate cover
2.15 All clinical areas providing care for children and young people with endocrine disorders have appropriate paediatric formularies.	NSF, Medicines for Children and Young People 2004[14]	Availability of paediatric formularies	Availability of paediatric formularies
2.16 Play specialists are employed in all appropriate areas of the service.	National Service Framework for Children, Young People and Maternity Services 2004[4]	Availability of play specialists within departments	Employment register
2.17 A child psychologist is available within the service (Appendix 1).	National Service Framework for Children, Young People and Maternity Services 2004[4]	Access to CAMHS	Availability of CAMHS
2.18 Sufficient equipment, complying with national standards, is in place to meet the requirements of each service.	The National Measurement Programme 2009[15]	Existence of appropriate auxological equipment	Availability
2.19 Resources are available to support parent/family training.	RCN Competencies: an integrated career and competency framework for paediatric endocrine nurse specialists 2008[13]	Availability of education resources to support parent/family training	Audit and patient satisfaction questionnaire
2.20 Facilities for parents are available on site at all inpatient settings for children and young people. These include: • Overnight accommodation. • Sitting room. • Quiet room/area for private conversation. • Facilities for making refreshments. • Telephone.	National Service Framework for Children, Young People and Maternity Services 2004[4] Standards for Children in Hospital: A guide for parents and carers 2003 [16]	Adherence to national standard	Patient satisfaction questionnaire

• Access to networking with other parents.			

Standard 3: Environment and facilities, care of the child and family/patient experience.

Rationale: All children and young people are cared for in a child friendly environment with suitable facilities and equipment for their age and developmental needs.

Standard	Evidence and/or guidance	Metric	Measurement method
3.1 Services are delivered in line with the principles of the UN Convention on the Rights of the Child.	General Assembly of the United Nations 1989[17]	Service delivered according to guidance	Adherence to guidance
3.2 Children, young people and their families are aware of the options available to them in their care management in order to make an informed choice.	Medicines adherence: Involving patients in decisions about prescribed medicines and supporting adherence, NICE 2009[18]	Availability of choices	Patient satisfaction survey
3.3 Facilities for day case investigations for children with endocrine disorders are available at the lead centre.	Consensus	Availability of day case facilities	Existence and audit of facilities
3.4 Parent/carers are actively encouraged to participate in care.	National Service Framework for Children, Young People and Maternity Services 2004[4] RCN Competencies: an integrated career and competency framework for paediatric endocrine nurse specialists 2008[13]	Availability of educational packages for patients and families	Audit of written information provided to patients and their families Patient/parent satisfaction survey
3.5 Information and training is available for children, young people and their families about services, their condition and care.			
3.6 Information and training is provided for children, young people and their parents/carers who wish to be involved in delivering elements of their own/their child's care.			
3.7 Whenever parents/carers stay in hospital to help care for a child, consideration is given to their practical needs, including regular breaks for personal needs, to obtain food/drink, make telephone calls etc.	National Service Framework for Children, Young People and Maternity Services 2004[4] Standards for Children in Hospital: A guide for parents and carers 2003[16]	Adherence to national standard	Patient satisfaction questionnaire
3.8 Information and support is given to parents and families on how to access funds to travel to and from a specialist centre where necessary.	National Service Framework for Children, Young People and Maternity Services 2004[4] RCN Competencies: an integrated career and competency framework for paediatric endocrine nurse specialists 2008[13]	Documented evidence of links with support groups Availability of information within the outpatient clinic	Patient satisfaction questionnaire Audit of available information and service evaluation survey
3.9 Information is available for children, young people and their families in several formats about their condition including leaflets and/or videos/DVD's in an appropriate language.			
3.10 Families are provided with contact details for available support groups.			
3.11 At both local and national level, there are robust links in place with the voluntary services			

that provide additional support to children, young people, parents and families.			

3.12 Transition pathways are in place to allow for seamless transition to adult services (Appendix 1).	Transition: getting it right for young people Improving the transition of young people with long term conditions from children's to adult health services 2006[9]	Any patient in transition from paediatric to adult care should have a defined and agreed plan for handover of care.	Rapid quality review of patients' notes

3.13 The needs of adolescents are recognised and met within the organisation including age appropriate inpatient and outpatient facilities.	National Service Framework for Children, Young People and Maternity Services 2004[4]	Provision of appropriate outpatient and inpatient facilities for adolescents	Existence of appropriate facilities

3.14 Consent protocols are in place based on local/national recommendations.	Reference guide to consent for examination or treatment, second edition 2009 [19]	Usage of national guidelines	Audit of consent for procedures

3.15 In the case of the death of a child or young person, protocols are in place to ensure information is cascaded to link paediatricians, general practitioners and all members of the MDT involved in their care.	Working Together to Safeguard Children. *A guide to inter-agency working to safeguard and promote the welfare of children*[20]	Documentation of protocols	Case note review

3.16 When children and young people require two or more ongoing specialist services, effort should be made to co-ordinate care by a key worker. The name of the key worker is made known to the child, young person and their family and is recorded in their care plan.	National Service Framework for Children, Young People and Maternity Services 2004[4]	Existence of key worker for children with complex disorders	Rationalisation of outpatient appointments

3.17 All children and young people have access to ongoing educational opportunities whilst an inpatient or when receiving follow up care.	Access to education for children and young people with medical needs 2002 [21] Meeting the educational needs of children and young people in hospital 2003[22]	Access to education during inpatient visits	Audit

3.18 Appropriate consent to physical examination and treatment is obtained for all children and young people and chaperoning is available where necessary.	Good Medical Practice 2006[23]	Compliance with the guideline	Patient satisfaction survey Complaints

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.

Standard	Evidence and/or guidance	Metric	Measurement method
4.1 There is effective two-way communication using a variety of methods between specialist services and secondary and primary care.	Informing Healthcare. Transforming Healthcare using Information and IT[24] The report of the public inquiry into children's heart surgery at the Bristol Royal Infirmary[25] Consensus	Appropriate IT systems are in place Discharge summaries Patient databases	Notes audit Patient satisfaction survey
4.2 IT links are in place to support the network, including cross border arrangements with other lead centres.			
4.3 Lead and specialist centres maintain, with administrative staff, a database of patients.			
4.4 Children, young people and their families have the opportunity to contribute to a patient satisfaction process as part of their annual review of care.			
4.5 Appropriate levels of communication exist between health professionals and children and young people and their families e.g. contact telephone numbers for emergencies, email addresses, access to OPD, clinic appointment times etc			

Standard 5: Clinical Governance, Professional Education and Training and Evidence Base.

Rationale: Endocrine services are staffed with appropriate multi-disciplinary professionals who are fully trained and supported to maintain their continuing professional development. High quality evidence based care is used when available.

Standard	Evidence and/or guidance	Metric	Measurement method
5.1 All paediatricians and specialist nurses responsible for endocrine service delivery have undertaken specialist endocrine training to an appropriate level and continue to maintain their knowledge and skills through continuous professional development (CPD) and have protected time and funding to allow them to do this.	A Framework of Competences for Core Higher Specialist Training in Paediatrics 2005[26] European Society for Paediatric Endocrinology (ESPE) training syllabus 2001[27] RCN Competencies: an integrated career and competency framework for paediatric endocrine nurse specialists 2008[13] CSAC	CCST CPD certificates Comparison to BSPED and ESPE guidelines	Registration with an appropriate body for monitoring CPD Adherence to guidelines/ CSAC approval Appraisal documentation re safeguarding training
5.2 All paediatricians and specialist nurses caring for children and young people with endocrine disorders should be familiar with local safeguarding procedures.			
5.3 Lead centres are accredited training centres. [3](Appendix 3)			

5.4 An induction programme is in place for all new members of staff.	Care Quality Commission Inspection guides and the Department of Health's core standards 2004 [28]	Existence of an induction programme	Documentary evidence of attendance at induction programme for new staff

5.5 Staff using specific equipment are given formal training in its use.	National Service Framework for Children, Young People and Maternity Services 2004[4] Consensus	Departmental audits Clinical care pathways Availability of reports from MCN's	Availability of audit/reports and documentation of changes made Use of care pathways Service evaluation
5.6 As part of the network, clinical pathways, protocols and guidelines are developed for the care and management of children and young people with specific endocrine disorders.			
5.7 Audit programmes are funded as part of the MCN arrangements and include comprehensive audit of: • Training • Practice • Compliance with pathways and protocols • Agreed outcomes			
5.8 Multi-disciplinary research is an essential component of the MCN.			
5.9 All members of the MCN have access to legal, ethical and psychological support from the relevant Trusts and Lead Centres for clinical decision making.			
5.10 Each MCN produces an annual clinical governance report.			

GLOSSARY :

ALD	Adrenoleukodystrophy
BSPED	British Society for Paediatric Endocrinology and Diabetes
CAH	Congenital Adrenal Hyperplasia
CAMHS	Child and Adolescent Mental Health Services
CCST	Certificate of completion of specialist training
CPA	Clinical Pathology Accreditation
CPD	Continued Professional Development
CSAC	College Specialist Advisory Committee
CYPSSP	Children and Young Person's Specialist Services Project
DGH	District General Hospital
DXA	Dual X-ray Absorptiometry
EQA	External Quality Assurance
ESPE	European Society for Paediatric Endocrinology
GMC	General Medical Council
IT	Information Technology
MCN	Managed Clinical Network
MDT	Multi Disciplinary Team
MRI	Magnetic Resonance Imaging
NSF	National Service Framework
OPD	Out Patient Department
RCN	Royal College of Nursing
RCPCH	Royal College of Paediatrics and Child Health
SSNDS	Specialist Services National Definition Set

APPENDIX 1

Lead Centre Specialist Paediatric Endocrine Team

- Paediatric Endocrine Consultant (1 per 500,000 total population). A lead centre will require enough paediatric endocrinologists to provide an on-call rota.
- Specialist Registrar in Endocrinology
- Specialist Paediatric Endocrine Nurses and Auxologist
- Specialist Paediatric Dieticians and access to a Nutrition MDT
- Psychologist and access to CAMHS
- Administrative Support
- Clinical Geneticist
- Data Clerk
- Access to a Paediatric Pharmacist
- Clinical Biochemist
- Paediatric Surgeon and Paediatric Urologist
- Adult Endocrinologist
- Adult Diabetologist
- Adolescent Gynaecologist
- Access to a Paediatric Radiologist
- Access to Medical Physicist with expertise in DXA scanning

District General Hospital Paediatric Endocrine Team

- Pediatrician with an interest/link paediatrician
- Paediatric Dietitian
- Paediatric Nurse identified with an endocrine interest and link with specialist nurse(s) at lead centre
- Access to CAMHS
- 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

APPENDIX 2

Specialised Clinical Biochemistry

- Peptide hormone services
- Steroid assay services

Standards relating to clinical biochemistry

All centres where children are admitted should have access to a 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 District General Hospitals. 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.

APPENDIX 3

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 BSPED on behalf of the Royal College of Paediatrics and Child Health (RCPCH) and recognised by the General Medical Council (GMC).

Full Training Centre
The centre must provide adequate experience in all fields of paediatric 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 science 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.

References

[1] Children and Young People's Specialised Services Project (CYPSSP). All Wales Endocrine Standards for Children and Young People's Specialised Healthcare Services 2009. http://www.wales.nhs.uk

[2] SSNDS Definition No.23 Specialised Services for Children (3rd Edition) 2009/10, Specialised Paediatric Endocrinology and Diabetes Services pg 40. National Specialised Commissioning Group http://www.ncg.nhs.uk/index.php/key-documents/specialised-services-national-definitions-set/

[3] Commissioning Safe and Sustainable Specialised Paediatric Services – A framework of Critical Inter-Dependencies 2008 Department of Health
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_088068

[4] National Service Framework for Children, Young People and Maternity Services 2004 www.dh.gov.uk

[5] Modelling the Future I, A consultation paper on the future of
children's health services, September 2007, Royal College of Paediatrics and Child Health www.rcpch.ac.uk

[6] Modelling the Future II. Reconfiguration and workforce estimates, 2008, Royal College of Paediatrics and Child Health www.rcpch.ac.uk

[7] Modelling the Future III. Safe and sustainable integrated health services for infants, children and young people, December 2009, Royal College of Paediatrics and Child Health www.rcpch.ac.uk

[8] Newborn bloodspot screening in the UK. Policies and Standards April 2005 http://newbornbloodspot.screening.nhs.uk

[9] Transition: getting it right for young people. Improving the transition of young people with long term conditions from children's to adult health services 2006 www.dh.gov.uk/childrensnsf

[10] A practical guide to bone densitometry in children, National Osteoporosis Society, November 2004 www.nos.org.uk

[11] Human growth hormone (somatropin) for the treatment of growth failure in children. Review of NICE technology appraisal guidance 42 http://www.nice.org.uk/nicemedia/live/12992/48715/48715.pdf

[12] British Society for Paediatric Endocrinology and Diabetes website:
http://www.bsped.org.uk/professional/guidelines/index.htm

[13] RCN Competencies: an integrated career and competency framework for paediatric endocrine nurse specialists, 2008, Royal College of Nursing

[14] Medicines Standard: National Service Framework for Children, Young People & Maternity Services 2004 www.dh.gov.uk

[15] The National Measurement Programme 2009, Dept of Health www.dh.gov.uk

[16] Standards for Children in Hospital: A guide for parents and carers 2003, Dept of Health www.dh.gov.uk

[17] General Assembly of the United Nations (1989). The Convention on the Rights of the Child. Adopted by the General Assembly of the United Nations on 20th November 1989

[18] Medicines adherence Involving patients in decisions about prescribed medicines and supporting adherence, 2009 NICE clinical guideline 76

[19] Reference guide to consent for examination or treatment, second edition 2009 www.dh.gov.uk

[20] Working Together to Safeguard Children. A guide to inter-agency working to safeguard and promote the welfare of children, March 2010, Department of Children, Schools and Families, HM Government http://publications.dcsf.gov.uk

[21] Access to Education for children and young people with Medical needs 2002 www.dfes.gov.uk/sickchildren

[22] Meeting the educational needs of children and young people in hospital. A design guide. Building Bulletin 96,2003 www.tso.co.uk/bookshop

[23] Good Medical Practice 2006, GMC http://www.gmc-uk.org/guidance/good_medical_practice.asp

[24] Welsh Assembly Government (July 2003) Informing Healthcare. Transforming Healthcare using Information and IT. http://wales.gov.uk/topics/health/publications/health/reports/informinghealthcare?lang=en

[25] Kennedy I, Howard R, Jarman B, Maclean M (2001) Learning from Bristol: The report of the Public Inquiry into children's heart surgery at the Bristol Royal Infirmary 1984-1995. Norwich: HMSO

[26] A Framework of Competences for Core Higher Specialist Training in Paediatrics October 2005, RCPCH, www.rcpch.ac.uk

[27] The European Training Syllabus in Paediatric Endocrinology and Diabetes 2001, www.eurospe.org

[28] Care Quality Commission, Inspection guides and the Department of Health's core standards 2004 www.cqc.org.uk