# UK standards for Paediatric Endocrinology

April 2024

British Society for
Paediatric Endocrinology
and Diabetes

Endorsed by:

RCPCH
Royal College of
Paediatrics and Child Health
*Leading the way in Children's Health*

## Contents

## Foreword

The UK standards for paediatric endocrinology have been developed by the British Society for Paediatric Endocrinology and Diabetes and are endorsed by the Royal College of Paediatrics and Child Health. They were initially published in 2019 and have been reviewed and updated for 2024.

The standards apply to all children and young people aged 0-18 years with an endocrine condition. The aims of the standards are to reduce variability in care and to ensure that equitable services providing high quality, safe and effective care are available to all children and families across the UK.

The standards are intended for healthcare professionals and for service commissioners to plan, deliver and quality assure paediatric endocrine services.

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**Chair, British Society for Paediatric Endocrinology and Diabetes**

# Definitions

## Children

Infants, children and young people under the age of 18 years across the UK.

## Lead Specialist Centre for Paediatric Endocrinology

The Lead Specialist Centre provides a comprehensive multidisciplinary service for tertiary paediatric endocrine conditions for investigation, treatment and management of children with endocrine disorders with co-location of appropriate specialised paediatric services (appendix 1).

## Network centre

Network centres have at least one consultant paediatrician with expertise in paediatric endocrinology.

## Regional Clinical Network

These are paediatric endocrine services composed of the Lead Specialist Centre and Network centres brought together across a region through informal links to provide high quality, specialist paediatric endocrine care to the local population.

## Managed Clinical Network

A funded regional clinical network with defined objectives and structure, clear governance framework and an identified network lead to ensure shared protocols and effective communication.

## Outreach clinic

A multidisciplinary clinic undertaken by the lead specialist centre at a network centre. The outreach clinic will include the consultant paediatric endocrinologist, the local consultant paediatrician with expertise in endocrinology and the paediatric endocrine nurse specialist.

## Introduction

Paediatric endocrinology is concerned with the diagnosis and management of children with growth, hormonal, bone and mineral disorders. This document provides recommendations for standards of care for services managing children with these conditions.

Most common endocrine conditions are variations of normal development, growth and puberty, and are managed in a network centre or in conjunction with primary care. More complex and rare conditions are managed by a lead specialist centre in conjunction with the regional clinical network.

In some instances local investigations may reveal more complex conditions requiring referral to the lead specialist centre. Network centres, general paediatricians or parents may request a second opinion from the lead specialist centre to confirm a non-specialist endocrine diagnosis that subsequently can be managed at a network centre.

## Location of care for paediatric endocrine conditions

The complexity of the endocrine condition, and the need for other specialised services with associated multidisciplinary teams (MDTs), determines where a child will be managed[1,2,3]. There are 22 designated lead specialist centres for paediatric endocrinology in the UK (appendix 2). Some conditions require MDT input from a number of other specialists at joint clinics at the lead specialist centre necessitating attendance at the lead specialist centre for some visits.

Some children will need to access nationally commissioned services for certain rare paediatric endocrine conditions (these are not covered by this document and commissioning arrangements may vary across the home nations) and access to these services will usually be through the lead specialist centre[4]. The nationally commissioned services are for Alström syndrome, Bardet Biedl syndrome, complex childhood osteogenesis imperfecta, congenital hyperinsulinism, gender identity development service for children and adolescents, insulin resistant syndromes, Wolfram syndrome and Complications of Excess Weight [4].

### Conditions managed by the lead specialist centre for paediatric endocrinology

The following conditions are managed by the lead specialist centre, through outreach clinics at a network centre or through shared care between the lead specialist centre together with the network centre[1-3,5].

**Endocrine Disorders**

- complex growth problems including Turner syndrome and growth hormone deficiency; puberty disorders including precocious, delayed or absent puberty
- pituitary disease including hypopituitarism, pituitary and peri-pituitary tumours
- complex fluid balance problems (e.g. in neurosurgery)
- thyroid and associated disease including thyroid malignancy and thyrotoxicosis and parathyroid disease, but not including autoimmune or congenital hypothyroidism
- parathyroid disorders
- disorders of the adrenal glands
- endocrine disorders associated with chronic disease e.g. care of endocrine problems in cancer survivors, growth and pubertal problems associated with chronic renal failure and inflammatory bowel disease
- severe or repeated non-ketotic hypoglycaemia
- disorders of bone and calcium metabolism
- genetic endocrine tumour syndromes, multiple endocrine neoplasia and other familial endocrine disorders
- differences of sex development (DSD)

- severe obesity (BMI SDS>99.6th centile with one or more co-morbidities or BMI > +3.3SDS). In England, these services are commissioned separately by NHSE as CEW (Complications of Excess Weight) clinics.

**Diabetes Disorders**

- diabetes complications in childhood (e.g. nephropathy, complex compliance problems such as eating disorders)
- Rare forms of diabetes, in conjunction with the diabetes network (e.g. neonatal diabetes, maturity onset diabetes of the young (MODY))
- insulin resistance syndromes
- diabetes associated with chronic disease (high dose steroid usage in the treatment of some cancers).
- morbid obesity associated with Type 2 diabetes.
- cystic fibrosis related diabetes

### Conditions managed at network centres in the regional clinical network for paediatric endocrinology

These conditions are managed by a paediatrician with expertise in endocrinology at a network centre, and may require input from the lead specialist centre on a shared care basis with the local team[5]. For some conditions the initial diagnostic investigations may need to be undertaken at the lead specialist centre.

- Primary hypothyroidism (congenital and acquired)
- Delayed puberty in boys
- Variations of early pubertal development in girls
- Vitamin D deficiency
- Familial short and tall stature children
- Nutritional obesity

### Conditions managed by a general paediatrician at a district general hospital

These are conditions where there is a low requirement for input from a paediatrician with expertise in endocrinology[5]. These cases will be managed by the local general paediatrician at a District General Hospital (DGH) in conjunction with primary care:

- Familial short and tall stature children
- Nutritional obesity
- Vitamin D deficiency

## UK standards for paediatric endocrinology 2010

Paediatric endocrinology is a designated specialised service in the UK[1-3]. The first UK Paediatric Endocrine Standards were developed by the Clinical Committee of the British Society for Paediatric Endocrinology and Diabetes (BSPED) and published in 2010[5]. The standards emphasised the need for well-developed funded/managed regional clinical networks across the UK with excellent interactions between network centres and each lead specialist centre. It was recognised that appropriate use of primary, secondary and tertiary care was required and clear patient pathways should be established to ensure delivery of specialised paediatric endocrine care as close to the patient's home where possible. Standards were developed in five domains covering all areas of paediatric endocrine care. For each standard, evidence and/or guidance was cited.

## Impact of the 2010 UK standards for paediatric endocrinology

- The BSPED UK paediatric endocrine standards 2010 were adopted by NHS England for the service specifications for tertiary paediatric endocrine services[1] and used as the basis for paediatric endocrine standards in Scotland[3]. This led to the publication of the NHS standard contract Paediatric Medicine: Endocrinology and Diabetes 2013/14, which was used as the basis for commissioning, planning and developing tertiary paediatric endocrine services in England[1]. Paediatric endocrine standards had been developed in 2009 for Wales and were congruent with the 2010 UK standards[2].

- In 2015, the RCPCH audited the service configuration of specialised services across the UK including paediatric endocrinology[6]. Findings from the audit showed that 85.8% of paediatric endocrine services are now part of a clinical network. The current situation is that many networks rely on informal arrangements between network centres and the lead specialist centre, for both planned and emergency paediatric endocrine care, rather than funded managed clinical networks[6].

- A key recommendation for access to tertiary paediatric endocrine services is the provision by the lead specialist centre of 24-hour telephone paediatric endocrine advice for the regional network and their acute paediatric services[1,5,7]. The number of paediatric endocrine units providing 24-hour telephone advice was 69.0% in 2017[8].

- The 2010 UK paediatric endocrine standards were used for the first peer-review of the 22 UK paediatric endocrine centres led by BSPED peer review teams from 2011 to 2017.

## Peer review of UK lead specialist paediatric endocrine centres 2011 - 2017

Subsequent to the publication of the 2010 standards, the BSPED executive established a peer review officer to lead and co-ordinate the process of peer review of lead specialist centres across the UK. From 2011 to 2017, BSPED peer review panels assessed all 22 lead specialist centres. These visits provided useful and contemporary information regarding the status and standards of paediatric endocrine care delivered at lead specialist centres. The second round of peer reviews started in 2018 and all centres will continue to be peer reviewed on a 5-6 yearly basis.

For a peer review visit at each lead specialist centre, the peer review panel consisted of a consultant paediatric endocrinologist, consultant general paediatrician with an interest in endocrinology and a paediatric endocrine nurse specialist (PENS).

Prior to each peer review visit, the lead specialist centre was required to provide a detailed report on their service and a questionnaire was sent to network centres across the regional clinical network.

At each peer review visit the peer review panel met with the paediatric endocrine team, trainees, paediatric surgery/urology, adult endocrinology, neurosurgery, paediatric oncology, clinical genetics, the care group management team and administrative and clerical staff. Since COVID, peer reviews have taken place remotely, reducing costs and the carbon footprint of travelling long distances. Following the peer review visit a summary report with recommendations was sent to the lead specialist centre and chief executive at each trust.

## Changes to paediatric endocrine care and service delivery since 2010

Since publication of the 2010 standards, significant progress has been made in the field of paediatric endocrinology that has impacted on the delivery of care. Advancements have been made in molecular diagnostics, national and international collaborations have been established to optimise care for rare endocrine diseases, new therapies have been developed, condition-specific national and international MDTs established, international consensus and evidence-based recommendations for the care of various paediatric endocrine conditions have been published. These advances are transforming the way paediatric endocrine care should be delivered.

Such progress, on the background of changes to NHS structure and investment since 2010, have resulted in key challenges to UK paediatric endocrine services which must be addressed to ensure future successful delivery of excellent care for children with endocrine conditions.

These challenges include:

- increasing discoveries of rare endocrine diseases requiring bespoke management
- increased specialisation within paediatric endocrinology
- increased requirement for condition-specific MDTs at local, national and international levels
- requirement for national and international collaboration to optimise care
- requirement for standardisation of care across the UK
- national (PBR) tariff for paediatric endocrinology in England reduced by 30% from 2016 -2018, with funding moving to block contracts since COVID.
- commissioning for paediatric specialist services in England devolved to Integrated Care Boards (ICBs), with no clear information on how funding will be sustained for centres covering multiple ICBs
- increased time required for surveillance for new therapies by both paediatric endocrine nurse specialists (PENS) and doctors
- increased pressures on network centres to deliver acute paediatric care
- changing patterns of referral to lead specialist centres
- increased reliance on PENS to deliver paediatric endocrine care
- recruitment, training and retention of PENS
- PENS directed to cover acute care of general paediatric patients at the expense of paediatric endocrine service delivery
- increased requirement for junior doctors to deliver general paediatric care at the expense of paediatric endocrine service delivery
- reduced availability of trained consultants in paediatric endocrinology to fill substantive posts in paediatric endocrinology at lead specialist centres
- sustaining training for junior paediatricians who wish to pursue an interest in paediatric endocrinology
- need for a database and administrative support at lead specialist centres to identify children with different endocrine conditions for access to new therapies, research opportunities and condition-specific national audit and service evaluation.

## Aims

The aims of the standards, and their key actions, are to ensure safe, effective and high quality care for children with endocrine conditions by,
- addressing challenges to paediatric endocrine services
- providing a framework for service commissioners and providers to plan services
- informing the second round of peer review of UK paediatric endocrine centres and their regional clinical networks to benchmark current services and identify best practice and service deficits
- developing quality indicators for robust monitoring of paediatric endocrine services across the UK.

## Scope

This document is concerned with standards of care for services managing paediatric endocrine conditions at:
- lead specialist centres
- network centres

This document does not cover:
- standards of care for individual paediatric endocrine conditions
- Type I and Type 2 diabetes
- Nationally Commissioned (Highly Specialised) Services for paediatric endocrine conditions

## UK standards for paediatric endocrinology 2019

A working group was established in 2018 to review and update the existing standards. The review team was composed of consultant paediatric endocrinologists, consultant paediatrician, paediatric endocrine nurse specialist, Royal College of Paediatrics and Child Health (RCPCH) representative and parent representatives.

The standards focussed on the following domains:

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

The working group appraised the UK 2010 paediatric endocrine standards to establish relevance, accuracy and whether cited standard documents were current. Existing standards were appraised following review of the following organisations published guidelines: Department of Health, NHS, GMC, RCPCH and specialist society guidelines. New standards were incorporated in light of new guidance, information from BSPED peer review visits and consensus.

The draft standards were circulated for comments to the RCPCH Research and Policy Divisional Committee, the BSPED clinical committee, the BSPED executive committee, BSPED members, and patient support groups.

## Review and update of 2019 UK standards for paediatric endocrinology

In 2024, the BSPED clinical committee has reviewed the 2019 UK standards for paediatric endocrinology. They have assessed their current relevance, accuracy and taken into account changes to the NHS structure and funding and updated them accordingly.

# UK standards for paediatric endocrinology: 2024

## Domain 1: Access to Specialised Paediatric Endocrine Services

**Rationale:** All children identified with an endocrine condition should have access to high quality, evidence or consensus 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 conditions have access to a lead specialist centre and regional clinical network in paediatric endocrinology (appendix 1*)* | NHS Standard Contract Paediatric Medicine: Endocrinology and Diabetes[1]<br>National Service Framework for Children, Young People and Maternity Services[9]<br>Facing the future: standards for children with ongoing heath needs[10]<br>Consensus | Service is compliant with NHS standard Contract Paediatric Medicine: Endocrinology and Diabetes, NSF guidelines<br>Evidence of outreach clinics in the regional network<br>Adherence to any current published condition-specific guideline e.g. NICE guidelines, congenital hypothyroidism ESPE consensus 2014[11,12]<br>Job planning<br>Waiting list times for outpatients, day case investigation, inpatient investigation<br>Referral times<br>Availability of condition-specific MDTs at lead specialist centre e.g. disorder of sex development MDT[13,15] | Quality review of patient notes/correspondence<br>Formalised links between lead specialist centre and network centres<br>Anonymised patient list in outreach clinic<br>Availability of outreach service<br>Audit of individual conditions e.g. time to commence levothyroxine in congenital hypothyroidism patients<br>Evidence of updated and defined clinical pathways and local guidelines<br>Annual appraisal of job plan with appropriate time allowed for service delivery<br>Compliance with local waiting list/referral time standards |
| 1.2 Children with endocrine conditions are managed at the appropriate location (introduction, page 5)<br>1.2.1 Children and young people with endocrine conditions have access to outreach clinics | | | |
| 1.3 Plans are made for every child requiring review by a member of the lead specialist team in one of the following ways:<br>• immediate in-patient transfer to a lead specialist centre<br>• outpatient/day case appointment at a lead specialist centre or outreach clinic appointment at the network centre.<br>• referral to another lead specialist centre<br>• assessment in a condition-specific MDT<br>• a named consultant at the lead specialist centre is identified to co-ordinate care<br>• virtual appointment / MDT clinic | | | |
| 1.4 Referrals to the paediatric endocrine service are triaged and responded to within five working days. Where appropriate, this should include advice to the referring centre regarding treatment and further investigation.<br>1.4.1 Non-urgent clinical communication is sent to the child's GP or referring healthcare professional within five working | | | |

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| days.<br>1.4.2 For non-urgent advice, a member of the lead specialist team provides an email or telephone response within five working days<br>1.4.3 The consultant paediatrician at the network centre will triage all endocrine GP referrals and where appropriate will carry out an initial assessment and investigations<br>1.4.4 Where a child's condition is unpredictable or requires further review within 5 days, the consultant paediatric endocrinologist must alert the GP or paediatrician within one working day<br>1.4.5 The consultant paediatrician at the network centre is responsible for maintaining an individualised up to date 'open access' (or equivalent) plan where required | | | |
| 1.5 Shared care protocols are in place for children and young people requiring investigations, diagnosis and management of endocrine disorders<br>1.5.1 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 | | Evidence of shared care protocols | |

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| 1.6 Telephone access to specialist consultant paediatric endocrine advice for healthcare professionals at the lead specialist centre is available 24 hours a day. It is not appropriate for the consultant to be taking every direct patient query and calls can be triaged to within the MDT<br>1.6.1 The telephone access to specialist consultant paediatric endocrine advice is available to staff in primary, secondary and tertiary care within the regional clinical network.<br>1.6.2 Telephone advice requests outside normal working hours should be from the acute general paediatric or tertiary consultant to the consultant paediatric endocrinologist at the lead specialist centre (consultant to consultant).<br>1.6.3 Children, young people, their families and health professionals have access to clear instructions and consultant/ specialist nurse advice during routine working hours at the lead specialist centre.<br>1.6.4 Children and young people who are under the care of the endocrine service, and their families, have access, outside working hours, to advice and emergency care from local on-call services | NHS Standard contract Paediatric Medicine: Endocrinology and Diabetes[1]<br>Facing the future: standards for acute general paediatric service revised 2015 (RCPCH)[7]<br>Facing the future: standards for children with ongoing heath needs (RCPCH 2018)[10]<br>Consensus | On call rota<br>Complaints about service<br>Anonymised high level incidents and action points | Availability of on call rota<br>Patient satisfaction survey<br>Audit of emergency admissions of children and young people with endocrine disorders |

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| 1.7 A transition pathway is in place for all young people with endocrine disorders to transfer to adult services. | NHS updated guidelines 2016. Transition from children's to adults' services for young people using health or social care services[14] | Any patient in transition from paediatric to adult care should have a defined and agreed plan for handover of care.<br>Evidence of generic Transition pathways detailing Transition process<br>Transition/ Adolescent and Young Adult clinics | Rapid quality review of patients' notes<br>Patient satisfaction survey |

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| 1.8 Children and young people with a gynaecological endocrine condition have the opportunity to be seen by a gynaecologist with an interest in paediatric and adolescent gynaecology. | British Society for Paediatric and Adolescent Gynaecology: Clinical standards for service planning in paediatric and adolescent gynaecology[15] | Availability of specialist gynaecological services for children and young people<br>Designated lead for paediatric and adolescent gynaecology at the Lead specialist centre | Rapid quality review of patients' notes |
| 1.8.1 Children and young people with a gynaecological endocrine condition have the opportunity to be seen by specialised adolescent gynaecological services at the lead specialist centre. | Consensus | | |

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| 1.9 Access to imaging:<br>• urgent MRI at the lead specialist centre or network centre (for non-neurosurgical emergencies) is available and discussed with a paediatric radiologist within 24 hrs<br>• non urgent MRI scans (including those under general anaesthetic) are available and reported on by a paediatric radiologist within 8 weeks at the lead specialist centre and network centres<br>• pelvic ultra-sound scanning is available and reported on by a radiologist with an interest in paediatric imaging within 12 weeks at all network centres with link to the lead specialist centre for complex cases.<br>• radiology services to determine and report bone age is available whenever a child attends their hospital appointment.<br>• isotope scanning is available at lead specialist centres<br>• dual energy x-ray absorptiometry (DXA) is undertaken in centres with expertise in bone densitometry in children on machines calibrated for children. Scans are reported on within 4 weeks at all lead specialist centres and a lead clinician is identified to link with medical physics for DXA.<br>• vertebral fracture assessment should be undertaken where appropriate | Consensus<br>A practical guide to bone densitometry in children, National Osteoporosis Society, November[16] | Number of patients receiving investigation within the time frame<br>Time taken from investigation to reporting. | Notes audit/patient feedback, radiology audit trail. |

## Domain 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 will be supported by other essential resources to deliver care safely and effectively. In particular there is a need for access to inpatient beds at the lead specialist centre for management of complex patients, presence of a day case investigation unit at the lead specialist centre and co-location of other paediatric specialities at the lead specialist centre (see appendix 1)

| Standard | Evidence and/or guidance | Metric | Measurement method |
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| 2.1 There is a fully resourced multi-disciplinary team at the lead specialist centre with a capacity for outreach clinics (appendix 1).<br>2.1.1 There should be one WTE consultant paediatric endocrinologist at the lead specialist centre per 500,000 population covered by the regional clinical network<br>2.1.2 There should be 1.0 WTE Paediatric Endocrine Nurse Specialist per 750,000 population covered by the regional clinical network at the lead specialist centre. Paediatric endocrine nurses should be a minimum AfC band 6 with at least 1.0 WTE band 7 at the lead specialist unit.<br>2.1.3 Paediatric endocrine nurse specialists should have time and funding available for access to specialist education, both within their centre and by participation in appropriate courses.<br>2.1.4 Paediatric endocrine nurse specialists will have an active role in clinics, outreach clinics and actively participate in MDT meetings, service review and development<br>2.1.5 The lead specialist centre is supported by secretarial staff and database support to deliver service requirements and registry data entry<br>2.1.6 The clinic booking rules (clinic template) for a general paediatric endocrine (4 hour) clinic at the lead specialist centre | NHS Standard Contract Paediatric Medicine: Endocrinology and Diabetes[1]<br>Model contract for consultants in NHS organisations (version 5, April 2018)[17]<br>Academy of Medical Royal Colleges: Advice on Supporting Professional Activities in Consultant Job Planning[18]<br>RCPCH: The Paediatrician's Handbook[19]<br>Consensus | A multi-disciplinary team outlined in Appendix 1 is available<br>Job plan<br>Consensus | Manpower survey<br>Peer review<br>Local and regional Audit<br>Analysis of job plan against workload<br>Review specialist nurse appraisals for evidence of learning and active participation in team MDT |

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| or outreach clinic usually includes a combination of new and follow up patients. This ratio may vary from 1-3 new patients and 6-8 follow up appointments, (this may depend on complexity, and balance between face to face and telephone appointments.<br>2.1.7 The clinic template for condition-specific clinics or specialised MDT clinics at the lead specialist centre will be variable and specific to the condition. | | | |
| 2.2 The network centre is resourced to provide the local element of specialised endocrine care in partnership with the lead specialist centre (appendix 1) | | | |
| 2.3 A 10 PA job plan for a consultant paediatric endocrinologist should include<br>a. DCC allocation for clinics and separate DCC allocation for the patient administration that comes from each clinic<br>b. DCC allocation for chronic patient management between clinic visits and liaising with network centres<br>c. DCC allocation for each of: MDTs, inpatient management, supervision of day case investigations<br>d. DCC allocation for on call telephone advice<br>e. DCC/SPA allocation for attendance at network meetings (regional and national)<br>f. DCC allocation for travel to outreach clinics<br>g. DCC allocation for safeguarding<br>h. 0.25-0.5 SPA allocation for endocrine service and regional network development<br>i. SPA allocation for revalidation<br>2.3.1 Every DGH should have a designated lead for paediatric endocrinology (to be designated a network centre) and have formal links with the lead specialist centre and regional clinical network in paediatric endocrinology<br>2.3.2 Paediatricians at network centres (appendix 1) should have | | | |

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| defined sessions in their job plan committed to outreach clinics and the regional clinical network in paediatric endocrinology, including network meetings. | | | |

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| 2.4 The lead specialist centre has co-location with other specialist services (appendix 1) | NHS Standard Contract Paediatric Medicine: Endocrinology and Diabetes[1] | NHS Standard Contract Paediatric Medicine: Endocrinology and Diabetes[1] | Patient satisfaction survey |
| 2.5 Specialist facilities are available at the lead specialist centre (as detailed in appendix 3). Some network centres will also have these facilities. | NHS Standard Contract Paediatric Medicine: Endocrinology and Diabetes[1] | Biochemistry assay facilities as outlined in Appendix 3 are available for routine and complex endocrine investigations | Audit of available investigations at the local and lead centre. |

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| 2.6 Facilities are available at lead specialist centres and network centres to provide radiological investigations and expert interpretation. (see 1.9) | See 1.9<br>Delivering quality imaging services for children. Department of Health[20] | See 1.9 | See 1.9 |

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| 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/international guidance | Comparison of local protocols to BSPED/ESPE/international approved protocols |

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| 2.8 All children and young people requiring treatment with specialist endocrine drugs are funded / supported by shared care protocols. | Human growth hormone (somatropin) for the treatment of growth failure in children Technology appraisal guidance[21]<br>BSPED Clinical Standards for GH Treatment in Childhood & Adolescence[22]<br>BSPED Shared Care Guidelines: Paediatric use of Recombinant human Growth Hormone (r-hGH, Somatropin)[23]<br>BSPED Shared Care Guidelines: Use of Gonadotrophin Releasing Hormone (GnRH) Agonists – Triptorelin[24] | Funding is in keeping with NICE guidelines where available<br>Use of BSPED approved shared care protocols | Local audit against NICE guidance<br>Evidence of use of shared care protocols |

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| 2.9 There are allocated IT and administrative services to enable rapid transmission of clinical information across the network<br>2.9.1 A patient database is resourced at the lead specialist centre.<br>2.9.2 There are allocated IT resources at the lead specialist centre for participation in virtual MDTs | Consensus | Patient database/Electronic Patient Record<br>Hospital IT systems with intranet and internet access | Audit of letter times to referring HCP and/or information to parents<br>Evidence of use of patient database for condition-specific service evaluation, audit, collaboration, research |

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| 2.10 Workforce planning mechanisms are in place to allow for year on year growth and service development dependent on a local needs assessment. | RCPCH State of Child Health Short report series: The Paediatric Workforce[25]<br>Consensus | Success rate for business plans for service development<br>Service activity<br>Study leave allocation<br>Annual leave allocation | Service expansion<br>Monitoring of service activity to justify expansion and/or continuity and succession planning<br>Annual appraisal and CPD certification |
| 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 conditions, staffing is planned to allow for:<br>• study time<br>• attendance at MDT meetings<br>• CPD<br>• Annual leave<br>• Maternity leave<br>• sickness | | | |
| 2.13 In all units, administrative support is provided for a managed clinical network. | | | |

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| 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 Competences: an integrated career and competency framework for children's endocrine nurse specialists[26] | Compliance with the RCN competency framework | Review of nurses job plan to ensure adequate cover |

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| 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[27] | Availability of paediatric formularies | Availability of paediatric formularies |

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| 2.16 Play specialists are employed in all appropriate areas of the service. | National Service Framework for Children, Young People and Maternity Services 2004[9] | Availability of play specialists within departments | Employment register |

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| 2.17 A child psychologist is an integral part of the service (appendix 1). | NHS Standard Contract Paediatric Medicine: Endocrinology and Diabetes[1]<br>National Service Framework for Children, Young People and Maternity Services[9] | Access to CAMHS | Availability of CAMHS |

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| 2.18 Equipment, complying with national standards, is in place to meet the requirements of each service.<br>Appropriate auxology equipment must be available for<br>• measuring the length/height of infants, children and those with disabilities to the nearest millimetre<br>• measuring sitting height to the nearest millimetre.<br>• weighing all ages of children (scales must be digital)<br>All equipment should be in good working order, checked daily before use and calibrated at least annually.<br>2.18.1 Electronic growth charts should be available | The National Measurement Programme[28]<br>Consensus | Existence of appropriate auxological equipment | Availability |

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| 2.19 Resources are available to support parent/family training. | RCN Competences: an integrated career and competency framework for children's endocrine nurse specialists[26] | Availability of education resources to support parent/family training | Audit and patient satisfaction questionnaire |

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| 2.20 Facilities for parents are available on site at all inpatient settings for children and young people. These include:<br>• Overnight accommodation.<br>• Sitting room.<br>• Quiet room/area for private conversation.<br>• Facilities for making refreshments.<br>• Telephone.<br>• Access to networking with other parents. | National Service Framework for Children, Young People and Maternity Services[9]<br>Standards for Children in Hospital: A guide for parents and carers[29] | Adherence to national standard | Patient satisfaction questionnaire |

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| 2.21 Any child requiring dynamic hormone function testing should have been assessed previously by the paediatrician at the network centre or by the consultant paediatric endocrinologist at the lead specialist centre.<br>2.22 Endocrine day case investigations: must be undertaken by nurses or doctors who have knowledge of the conditions and protocols in a suitable clinical area with immediate access to support from other healthcare professionals if required.<br>2.23 Children having endocrine function tests should have beds or specialised chairs that are height adjustable and can be fully reclined in an emergency.<br>2.24 The clinical area for day case investigations must allow for maintaining the child and families dignity and privacy | Consensus | | |

## Domain 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 |
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| 3.1 Services are delivered in line with the principles of the UN Convention on the Rights of the Child. Article 24 of the UN Convention on the Rights of the Child (UNCRC) to ensure that no child is deprived of his or her right to access to health care services | General Assembly of the United Nations 1989[30] | Service delivered according to guidance | Adherence to guidance/ Evidence of deviation |
| 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, NICE Adherence 2015, Surveillance report 2016[31-33]<br>Facing the future: standards for children with ongoing heath needs[10]<br>BSPED clinical standards for GH treatment[23] | Evidence of availability of choices | Audit<br>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[9]<br>RCN Competences: an integrated career and competency framework for children's endocrine nurse specialists 2013[26]<br>BSPED clinical standards for GH treatment[23]<br>Clinical Standards for | Availability of educational packages for patients and families | Audit of written information provided to patients and their families<br>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. | | | |

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| | Management of an Infant or Adolescent presenting with a suspected disorder of sex development (DSD) DSD standards[13]<br>Facing the future: standards for children with ongoing heath needs[10] | | |

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| 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[9]<br>Standards for Children in Hospital: A guide for parents and carers 2003[29]<br>Facing the future: standards for acute general paediatric service revised 2015 (RCPCH)[7] | Adherence to national standard | Patient satisfaction questionnaire |

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| 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[9]<br>RCN Competences: an integrated career and competency framework for children's endocrine nurse specialists 2013.[26] | Documented evidence of links with support groups<br>Availability of information within the outpatient clinic | Patient satisfaction questionnaire<br>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/DVDs 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. | | | |

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| 3.12 Transition pathways are in place to allow for seamless transition to adult services | NHS updated guidelines 2016. Transition from children's to adults' services for young people using health or social care services[14]<br>Facing the future: | Any patient in transition from paediatric to adult care should have a defined and agreed plan for handover of care. | Evidence of MDT and audit of Transition process<br>Trust audit of compliance with NICE transition guidance |

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| | standards for children with ongoing heath needs[10] | | Departmental compliance with Trust transition standards |

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| 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[9]<br>Royal College of Physicians 2015: Acute care toolkit 13: Acute care for adolescents and young adults[34] | Provision of appropriate outpatient and inpatient facilities for adolescents<br>Access to a youth worker | Existence of appropriate facilities |

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| 3.14 Consent protocols are in place based on local/national recommendations. | Consent-to-treatment/children 2016[35] | Usage of national guidelines<br>Trust policy | Audit of consent for procedures |

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| 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[36]<br>Child Death Review Statutory Guidance[37] | Documentation of protocols<br>Trust level | Trust Policy<br>Audit |

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| 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[9] | Existence of key worker for children with complex disorders | Audit<br>Family feedback<br>Review of examples of outpatient appointment bookings |

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| 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[3]8<br>Meeting the educational needs of children and young people in hospital 2003[3]9<br>Statutory guidance Education for children with health needs who cannot attend school | Access to education during inpatient visits | Trust policy Audit |

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| | 2013[40] | | |

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| 3.18 Appropriate consent to physical examination and treatment is obtained for all children and young people and chaperoning is available where necessary. | GMC guidance updated on 25 May 2018 to reflect the requirements of the General Data Protection Regulation and Data Protection Act 2018[41]<br>Intimate examinations and chaperones, GMC 2013[42] | Compliance with the guideline | Trust/departmental chaperone policy<br>Patient satisfaction survey<br>Complaints |

# Domain 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 |
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| 4.1 There is clear and robust, effective, two way communication between specialist services and primary and secondary care, network centres and the lead specialist centre | Bringing Networks to Life[43]<br>Facing the Future: standards for children with ongoing health needs[10] | Appropriate IT systems are in place<br>Discharge summaries<br>Appropriate IT systems are in place | Audit of case notes/correspondence and regional networks |
| 4.2 Access to information systems including the child's shared electronic healthcare record | RCPCH and Us Voicebank[44] | Patient databases | |
| 4.3 Lead and network centres maintain a database of patients. | Consensus | | |
| 4.4 Children, young people, and their families are encouraged to contribute to a patient satisfaction process as part of their annual review of care. | | Evidence of contact details being communicated to families | Patient satisfaction survey<br>Patient satisfaction survey |
| 4.5 For appropriate levels of communication to exist between health professionals and children and young people and their families e.g. evidence of contact telephone numbers or, email addresses, to enable children/parents/carers to make enquiries between appointments | | | Numbers of service complaints relating to clinical communication<br>Serious safety incidents relating to communication |

# Domain 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. Endocrine services collaborate with general paediatricians and allied healthcare professionals, in functional networks.

| Standard | Evidence and/or guidance | Metric | Measurement method |
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| 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. | Paediatric Diabetes and Endocrinology Level 3 Paediatric Sub specialty syllabus[45]<br>European Society for Paediatric Endocrinology (ESPE) training syllabus 2021[46] | CCT in paediatric endocrinology or equivalent<br>CPD certificates<br>Comparison with BSPED and ESPE guidelines | Registration with an appropriate body for monitoring CPD<br>Adherence to guidelines/ RCPCH CSAC approval |
| 5.2 All paediatricians and specialist nurses caring for children and young people with endocrine disorders should be familiar with local safeguarding procedures. | RCN Competencies: an integrated career and competency framework for paediatric endocrine nurse specialists 2013[26] | | Annual Appraisal documentation and 360° Revalidation; Adherence to Safeguarding training |
| 5.3 Lead specialist centres are accredited training centres[3] (appendix 1 and 4) | RCPCH CSAC | Appendix 1 and 4 competencies | Adherence to Appendix 1 and 4 requirements |
| 5.4 An induction programme is in place for all new members of staff. | Care Quality Commission (CQC) Fundamental Standards | Existence and use of an up to date 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[9] | Departmental audits<br>Up to date clinical care pathways; | Availability of audit/reports and documentation of changes made |
| 5.6 As part of the regional clinical network, clinical pathways, protocols and guidelines are developed for the care and management of children and young people with specific endocrine disorders. | Regional clinical network consensus<br>Peer review<br>Consensus | Minutes of regional clinical network meeting demonstrating organisation of governance within network<br>Availability of reports from MCN's | Use of care pathways |
| 5.7 Audit programmes are organised within the regional clinical networks arrangements and include audit of:<br>• Training<br>• Practice<br>• Compliance with pathways and protocols | | Evidence of network functionality through network projects, minutes of organisational meetings and recording of protocol variance | Service evaluation |

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| - Agreed outcomes | | Minutes of regional clinical network meeting and attendee/circulation list | Evaluation of evidence |
| 5.8 The lead specialist centre and network centres will participate in BSPED peer review | | | |
| 5.9 The lead specialist centre and network centres will participate in national audit | | | |
| 5.10 All members of the regional clinical network have documented evidence of administrative and managerial support from the relevant Trusts and lead specialist centres covering legal and ethical bases for clinical decision making. | | | |
| 5.11 Each regional clinical network produces an annual clinical governance report. | | | |

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| 5.12 Paediatric endocrine nurses should be educated to degree level with expectation to work towards Masters level for career progression.<br>5.13 Paediatric endocrine nurses should be working towards achieving 'expert practitioner' level<br>5.14 Paediatric endocrine nurses should be a member of the BSPED and attend the annual BSPED meeting | RCN Competencies: an integrated career and competency framework for paediatric endocrine nurse specialists 2013[26]<br>Consensus | | |

# Acknowledgements

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BSPED clinical committee 2010

# GLOSSARY :

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| AfC | Agenda for change |
| BSPED | British Society for Paediatric Endocrinology and Diabetes |
| CCT | Certificate of completion training |
| CPA | Clinical Pathology Accreditation |
| CSAC | College Specialist Advisory Committee |
| DGH | District General Hospital |
| DSD | Disorder of sex development |
| DXA | Dual X-ray Absorptiometry |
| ESPE | European Society for Paediatric Endocrinology |
| GH | Growth hormone |
| 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 |
| PENS | Paediatric endocrine nurse specialist |
| PBR | Payment by results |
| RCN | Royal College of Nursing |
| RCPCH | Royal College of Paediatrics and Child Health |

# APPENDIX 1: Lead specialist centre and network centre paediatric endocrine teams

## Lead Specialist Centre Paediatric Endocrine Team

- Paediatric Endocrine Consultant - 1 per 500,000 regional network population*. A lead centre will require enough paediatric endocrinologists to provide an on-call rota continuously. (** this does not include diabetes)*
- Specialist Registrar in Endocrinology (ST 4+)
- Specialist Paediatric Endocrine Nurses (1 per 750,000 regional network population)
- Specialist Paediatric Dietitians and access to a Nutrition MDT
- Clinical Psychologist and access to CAMHS
- Administrative and database support
- Clinical Geneticist and access to cytogenetics and molecular genetics laboratory services
- Nominated Paediatric Pharmacist
- Clinical Biochemist, NEQAS accredited laboratory and access to endocrine-biochemistry MDT
- Paediatric Surgeon, Paediatric Urologist and Paediatric Neurosurgeon/Pituitary surgeon
- Access to Paediatric pathologist and histopathology services
- Access to Adult Endocrinologist and dedicated Transition services into Adolescent and Young Adult Endocrine services
- Adult Diabetologist
- Paediatric / Adolescent Gynaecologist
- Access to a Paediatric Radiologist, availability of electronic image transfer within network
- Access to nuclear medicine for isotope scanning and access to medical physicist Access to Paediatric High Dependency Unit and Paediatric Intensive Care Unit
- Access to tertiary Neonatal Intensive Care Unit and neonatologist
- Access to a Children's Safeguarding team
- Support from Information Management Team
- Support from Responsible Officer for Information Governance

## Specialised services that should be co-located with Paediatric Endocrinology[1]

Anaesthesia, Adult Endocrinology, CAMHS/ Psychosocial Support, Clinical Biochemistry, Neurosurgery, Neurology, Nutrition and Dietetic Services, Paediatric Intensive Care, Paediatric Urology, Paediatric Surgery

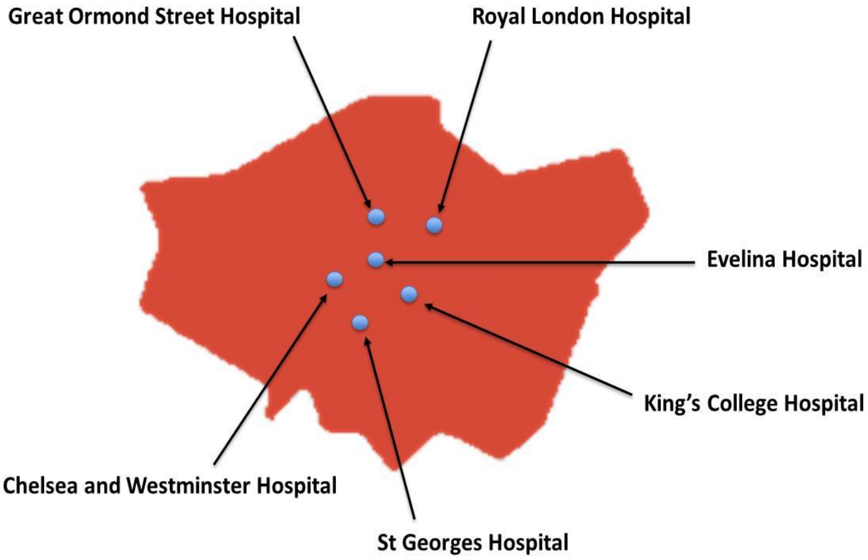
## Specialised services that are inter-dependent on Paediatric Endocrinology[1]

Cardiology, Dermatology, Diabetes, Gastroenterology, Genetics, Gynaecology, Haematology, Metabolic, Neonatal, Nephrology, Oncology, Orthopaedics, Palliative Care, Radiology, Respiratory, Rheumatology

## Network Centre Paediatric Endocrine Team

- Paediatrician with expertise in endocrinology/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 Radiologist with interest in paediatrics; availability of electronic image transfer facilities
- Access to a Paediatric Pharmacist
- Access to a Children's Safeguarding team
- Support from Information Management Team
- Support from Responsible Officer for Information Governance

## APPENDIX 2: Location of UK lead specialist centres for paediatric endocrinology



# APPENDIX 3: Specialised clinical biochemistry

## Specialised Clinical Biochemistry

- Validated Peptide hormone services
- Validated Steroid hormone 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. Services for specific investigations, e.g. serum cortisol, osmolality, thyroid function tests 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. There should be a system to alert clinicians of abnormal results both during working hours and outside working hours. The Clinical Biochemistry team should demonstrate MDT working with the paediatric endocrinology team and contribute to the Managed Clinical Network.

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.

While some specialist peptide hormone and steroid hormone services may not be available 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 4: Definitions of training centres

## 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 (with the exception of nationally commissioned services). There should be at least two consultant paediatric endocrinologists located at a full training centre. A full component of the Secondary and Tertiary Courses must be provided as per BSPED and ESPE Training syllabi. The number of inpatient and outpatient activities and episodes and range of paediatric endocrine pathology managed must be sufficient to provide suitable exposure and training for a specialty trainee in paediatric endocrinology. The centre should provide a rolling programme of training in paediatric endocrinology consisting of didactic, informal and bedside teaching arrangements, supplemented and reinforced by electronic/web-based modules linking directly to BSPED and ESPE Training syllabi. 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 (including participation in NIHR portfolio studies) and direct or indirect 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.

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