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| **Peer Review of Paediatric Endocrine Centres** |
| Self-Assessment and Peer-Assessment using  |
| 2019 UK standards for Paediatric Endocrinology |
| Form for Self-Assessment and Peer-Assessment |
| Prof Leena Patel, Dr John Schulga, Dr Indi Banerjee |
| May 2019 |



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**British Society for**

**Paediatric Endocrinology**

**and Diabetes**

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# Foreword

The BSPED Peer review process is based on the 2019 UK standards for paediatric endocrinology, developed by the British Society for Paediatric Endocrinology and Diabetes and endorsed by the Royal College of Paediatrics and Child Health.

The aims of the standards are to reduce variability in care, improve services, 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.

To determine whether centres are delivering safe, effective and high-quality care for children with endocrine conditions, Peer review aims to:

* benchmark current services against the UK Standards
* identify best practice and service deficits
* assess quality indicators for robust monitoring of paediatric endocrine services across the UK.

Peer review will not

* determine whether standards of care for individual paediatric endocrine conditions are being met
* assess services for Type I diabetes
* assess Nationally Commissioned (Highly Specialised) Services for rare paediatric endocrine conditions (Alström syndrome, Bardet Biedl syndrome, complex childhood osteogenesis imperfecta, congenital hyperinsulinism, gender identity development service for children and adolescents, insulin resistant diabetes and Wolfram syndrome).

**Dr Indi Banerjee, Peer Review Officer for BSPED**

# 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 a special interest 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 an interest in endocrinology and the paediatric endocrine nurse specialist.

# Glossary

|  |  |
| --- | --- |
| 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 |
| SPEC | Specialist Paediatric Endocrine Centre |

# Introduction

The UK Standards for Paediatric Endocrinology 2019 provide the framework for this Peer Review document. It incorporates both the Self-assessment by the Specialist Paediatric Endocrine Centre (SPEC) as well as the Assessment by the BSPED Peer Review team.

This Peer Review document includes the following sections:

Section 1. Information about the SPEC

Section 2. Site visit requirements

Section 3a. SPEC Self-assessment

Section 3b. Assessment by Peer Review team

Section 4. Conclusions and recommendations by Peer Review team

Section 5. Action plan by SPEC for recommendations provided from the peer review

Sections 1, 2 and 3a must be completed by the centre Lead on behalf of their centre and sent to the Peer Review team at least 4 weeks in advance of the site visit.

Before the site visit, the Peer Review team will review the information provided in Sections 1, 2 and 3a by the centre Lead. They will contact the centre Lead in good time for any additional information the team requires. Sections 3b and 4 will be completed by the Peer Review team during and after the site visit based on all information gathered.

**Section 5 will be completed by the centre Lead after the Peer Review. This will be shared with the Peer Review team within 2 months of the site visit.**

# CENTRE SELF-ASSESSMENT AND PEER REVIEW

This section includes tables in the 5 domains of the UK Standards for Paediatric Endocrine Care listed below.

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 experience

Domain 4. Communication

Domain 5. Clinical Governance, Professional education and Training, and Evidence Base

"Each domain is to be completed by the centre lead on behalf of their service.

Each standard in the domain should be self-assessed and Peer assessed using the grades as defined in the table below."

|  |  |  |
| --- | --- | --- |
| **GRADING for each standard in the domains** | **GRADING ABBREVIATION** | **DEFINITION for grade** |
| **Exceeded** | Exc | Very good practice |
| **Met** | Met | Evidence or information which shows the criterion is being met |
| **Unmet** | UnM | Evidence or information which shows the criterion is not being met |
| **Not applicable** | NA | Criterion not applicable to this endocrine centre |

# Confidentiality

The initial draft of this report will be confidential.

It will be shared with the centre reviewed and they will have an opportunity to correct any factual inaccuracies. The final version will go to the BSPED Officer for Peer Review and to no other party without the express permission of the centre lead.

In turn, those reviewed will have the opportunity to provide feedback on the review process to their Peer Review team.

|  |
| --- |
| **Record of thanks *to the lead organisers in the centre visited*** |
|   |
|  |  |  |
| **SPEC Lead** |
| Name | Position | Signature |
|   |   |   |
|  |  |  |
| **Peer Review team** |
| Name | Position | Signature |
|   |   |   |
|   |   |   |
|   |   |   |

# Section 1. INFORMATION ABOUT THE SPECIALIST PAEDIATRIC ENDOCRINE CENTRE

## 1.1 Catchment area and hospitals

|  |  |  |  |
| --- | --- | --- | --- |
|  |  | SPEC Lead to complete | Peer Review Team comments |
| 1 | Geographical catchment area |  |  |
| 2 | Catchment area total population |  |  |
| 3 | Catchment area age 1-16y population |  |  |
| 4 | Particular characteristics e.g. social deprivation, preponderance of ethnic minorities, rural access problems |  |  |
| 5 | Hospital where the SPEC is located |  |  |
| 6 | Other hospitals linked with the SPEC |  |  |

## 1.2 Lead Specialist Paediatric Endocrine Centre Team

### 1.2.1 The SPEC Team

|  |  |  |  |
| --- | --- | --- | --- |
|  |  | SPEC Lead to complete*This is about your current status. Please add details.* | Peer Review Team comments |
| 1 | No. of Paediatric Endocrine Consultants[[1]](#footnote-1) |  |  |
| 2 | No. of Specialist Registrars in Endocrinology (ST4+) |  |  |
| 3 | No. of Specialist Paediatric Endocrine Nurses and Total Full-time equivalent[[2]](#footnote-2) |  |  |

### 1.2.2 Paediatric Endocrine Consultants

|  |  |
| --- | --- |
|  | SPEC Lead to complete. *This is about the current status at your centre.* |
|  | Name of Consultant | Total no. of PAs for Paediatric Endocrinology | No. of DCC PAs for Paediatric Endocrinology | No. of SPAs for Paediatric Endocrinology |
| 1 |  |  |  |  |
| 2 |  |  |  |  |
| 3 |  |  |  |  |
| 4 |  |  |  |  |
| 5 |  |  |  |  |
| 6 |  |  |  |  |
| 7 |  |  |  |  |
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| 12 |  |  |  |  |
| 13 |  |  |  |  |
| 14 |  |  |  |  |
| 15 |  |  |  |  |

### 1.2.3 Other Professionals and Specialised Services

|  |  |  |  |
| --- | --- | --- | --- |
|  |  | SPEC Lead to complete*Tick if services available, and add comments.* | Peer Review Team comments |
| 1 | **Other professionals comprising the Paediatric Endocrine team:** |
| 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 | [ ]  |  |  |
| Paediatric Neurosurgeon/Pituitary surgeon | [ ]  |  |  |
| Access to Paediatric pathologist and histopathology services | [ ]  |  |  |
| Access to Adult Endocrinologist and access to Transition services into Adolescent and Young Adult Endocrine servicesAdult 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 Information Governance officer | [ ]  |  |  |
| 2 | **Specialised services that should be co-located with Paediatric Endocrinology** |
| Anaesthesia | [ ]  |  |  |
| Paediatric Intensive Care | [ ]  |  |  |
| 3 | **Specialised services that are inter-dependent on Paediatric Endocrinology** |
| Cardiology | [ ]  |  |  |
| Dermatology | [ ]  |  |  |
| Diabetes | [ ]  |  |  |
| Gastroenterology | [ ]  |  |  |
| Genetics | [ ]  |  |  |
| Gynaecology | [ ]  |  |  |
| Haematology | [ ]  |  |  |
| Metabolic | [ ]  |  |  |
| Neonatal | [ ]  |  |  |
| Nephrology | [ ]  |  |  |
| Oncology | [ ]  |  |  |
| Orthopaedics | [ ]  |  |  |
| Palliative Care | [ ]  |  |  |
| Respiratory | [ ]  |  |  |
| Rheumatology | [ ]  |  |  |

## 1.3 Network Centre Paediatric Endocrine Team

|  |  |  |  |
| --- | --- | --- | --- |
|  |  | SPEC Lead to complete on behalf of Network Centre*Please specify if there are any professionals/services not available at your Network centre.* | Peer Review Team comments |
|  | Paediatrician with an interest/link paediatrician | [ ]  |  |  |
|  | Paediatric Nurse identified with an endocrine interest | [ ]  |  |  |
|  | Paediatric Dietitian | [ ]  |  |  |
|  | 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 Safeguarding team | [ ]  |  |  |
|  | Access to Information Management Team | [ ]  |  |  |
|  | Support from Responsible Officer for Information Governance | [ ]  |  |  |

## 1.4 Conditions managed

|  |  |  |  |
| --- | --- | --- | --- |
|  |  | SPEC Lead to complete*Please specify if any conditions from the list are NOT managed by your centre* | Peer Review Team comments |
| 1 | Endocrine conditions managed by the lead SPEC |
|  | 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 disease including thyroid malignancy and thyrotoxicosis, but not including autoimmune or congenital hypothyroidism | [ ]  |  |  |
|  | parathyroid disorders | [ ]  |  |  |
|  | disorders of the adrenal glands | [ ]  |  |  |
|  | endocrine disorders associated with chronic disease e.g. endocrine problems in cancer survivors, growth, pubertal problems associated with chronic renal failure and inflammatory bowel disease | [ ]  |  |  |
|  | severe or repeated hypoglycaemia  | [ ]  |  |  |
|  | disorders of bone and calcium metabolism | [ ]  |  |  |
|  | genetic endocrine tumour syndromes, multiple endocrine neoplasia and other familial endocrine disorders | [ ]  |  |  |
|  | disorders of sex development (DSD) | [ ]  |  |  |
| 2 | Diabetes disorders managed by the lead SPEC |
|  | diabetes complications in childhood e.g. nephropathy, complex compliance problems such as eating disorders. | [ ]  |  |  |
|  | Type 2 or rare forms of diabetes e.g. neonatal diabetes, maturity onset diabetes of the young (MODY) | [ ]  |  |  |
|  | insulin resistance syndromes | [ ]  |  |  |
|  | diabetes associated with chronic disease e.g. cystic fibrosis or high dose steroids in the treatment of some cancers. | [ ]  |  |  |
|  | morbid obesity associated with Type 2 diabetes | [ ]  |  |  |
| 3 | Conditions managed by a paediatrician with an interest in endocrinology at a network centres in the regional clinical network |
|  | Primary hypothyroidism (congenital and acquired) | [ ]  |  |  |
|  | Delayed puberty in boys | [ ]  |  |  |
|  | Variations of early pubertal development in girls | [ ]  |  |  |
|  | Familial short and tall stature | [ ]  |  |  |
|  | Nutritional obesity | [ ]  |  |  |
|  | Vitamin D deficiency | [ ]  |  |  |
| 4 | Conditions managed by a general paediatrician at a DGH |
|  | Familial short and tall stature  | [ ]  |  |  |
|  | Nutritional obesity | [ ]  |  |  |
|  | Vitamin D deficiency | [ ]  |  |  |

## 1.5 Clinical workload

|  |  |  |  |
| --- | --- | --- | --- |
|  |  | SPEC Lead to complete*Please specify based on your most recent data* | Peer Review Team comments |
| 1 | No. of new patients with endocrine problems seen in OPD annually |  |  |  |
| 2 | No. of follow-up patients with endocrine problems seen in OPD annually |  |  |  |
| 3 | No. of day cases with endocrine problems seen annually |  |  |  |
| 4 | Breakdown of no. of new and follow-up patients seen annually in subspecialty clinics: |
|  |  | New | FU |  |  |
|  | General paediatric endocrinology |  |  |  |  |
|  | Growth |  |  |  |  |
|  | Turner syndrome |  |  |  |  |
|  | Disorders of sexual development |  |  |  |  |
|  | Late Effects of childhood cancer |  |  |  |  |
|  | Metabolic Bone |  |  |  |  |
|  | Thyroid |  |  |  |  |
|  | Adolescent/Transitional |  |  |  |  |
|  | Other |  |  |  |  |
|  |  |  |  |  |  |

## 1.6 Previous BSPED Peer Review for the SPEC

|  |  |  |  |
| --- | --- | --- | --- |
|  |  | SPEC Lead to complete | Peer Review Team comments |
| 1 | Date of the previous review |  |  |  |
| 2 | Major recommendations from the previous review |  |  |  |
| 3 | What has changed at the SPEC since the last review |  |  |  |

# Section 2. SITE VISIT REQUIREMENTS

This section includes information about the arrangements that the centre lead will need to make in advance of the site visit.

## 2.1 Documents to be made available for the Peer Review team

This form must be completed by the centre lead and sent to the Peer Review team at least 4 weeks in advance of the site visit.

The documents listed in the table below should be assembled and made available for the Peer Review team during the site visit. Information that is in electronic format should be shown to the Peer Review team by the centre lead.

|  |  |  |  |
| --- | --- | --- | --- |
|  |  | SPEC Lead to ensure these are available for the Peer Review Team (Tick if available) | Peer Review Team comments |
| 1 | Schedule for arrangements from 9am to 5pm on the day of the Site Visit | [ ]  |  |  |
| 2 | Endocrine centre handbook and/or website | [ ]  |  |  |
| 3 | Centre protocols | [ ]  |  |  |
| 4 | Share care guidelines | [ ]  |  |  |
| 5 | Patient information sheets | [ ]  |  |  |
| 6 | Patient medical records | [ ]  |  |  |
| 7 | Patient letters to GPs, carers | [ ]  |  |  |
| 8 | Commissioned surveys, e.g.* clinic appointment waiting times
* letter turnaround time
* MRI/DEXA waiting times
 | [ ]  |  |  |
| 9 | Clinical audit reports | [ ]  |  |  |
| 10 | Centre research summary | [ ]  |  |  |
| 11 | Report from previous BSPED Peer Review | [ ]  |  |  |
| 12 | *Other* | [ ]  |  |  |

## 2.2 Site Visit Schedule

The centre lead must liaise with the Peer Review team to plan the site visit schedule. The centre lead must make arrangements for the Peer Review team to interview members of the SPEC team and visit key sites at the centre.

### 2.2.1 Professionals and patients invited to meet the Peer Review team

|  |  |  |  |
| --- | --- | --- | --- |
|  |  | SPEC Lead to add names and to check arrangements.*Specify all persons invited and indicate if they are not available to attend on the day of the site visit* | Peer Review Team comments |
| 1 | Paediatric Endocrine consultants |  |  |
| 2 | Paediatric Endocrine Junior Doctors |  |  |
| 3 | Specialist endocrine nurses |  |  |
| 4 | Admin team staff |  |  |
| 5 | Hospital Management representatives |  |  |
| 6 | Patients and carers |  |  |
| 7 | Other professionals, e.g.* Biochemistry consultant
* Clinical geneticist
* Paediatric surgeon
* Paediatric urologist
* Paediatric neurosurgeon
* Adolescent gynaecologist
* Adult endocrinologist
 |  |  |
| 8 | *Other* |  |  |

### 2.2.2 Centre sites to be visited

|  |  |  |  |
| --- | --- | --- | --- |
|  |  | SPEC Lead to list | Peer Review Team comments |
| 1 | Outpatient clinic waiting area and consultation rooms |  |  |
| 2 | Outpatient auxology equipment |  |  |
| 3 | Day case unit |  |  |
| 4 | In patient facilities including ward, HDU, PICU |  |  |
| 5 | Endocrine team facilities for secretaries, junior doctors, specialist nurses and consultants |  |  |
| 6 | Unique facilities, e.g. clinical research facilities |  |  |
| 7 | *Other* |  |  |

# Section 3 CENTRE SELF-ASSESSMENT AND PEER REVIEW

This section includes tables in the 5 domains of the UK Standards for Paediatric Endocrine Care listed below.

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 experience

Domain 4. Communication

Domain 5. Clinical Governance, Professional education and Training, and Evidence Base

For each domain, part 3a is to be completed by the centre lead on behalf of their service. Part 3b will be completed by the Peer Review team. Each standard in the domain should be self-assessed and Peer assessed using the grades as defined in the table below.

|  |  |  |
| --- | --- | --- |
| **GRADING for each standard in the domains** | **GRADING ABBREVIATION** | **DEFINITION for grade** |
| Exceeded | Exc | Very good practice |
| Met | Met | Evidence or information which shows the criterion is being met |
| Unmet | UnM | Evidence or information which shows the criterion is not being met |
| Not applicable | NA | Criterion not applicable to this endocrine centre |

## 3.1 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** | **3a. Centre Self-assessment**Tick the Grade | **3b. Assessment by Peer Review Team**Tick the Grade | **Metric**From UK Paediatric Endocrine Standards 2019 | **Measurement method**From UK Paediatric Endocrine Standards 2019 |
|  | Grade | Centre comments | Grade | Peer review comments |  |  |
| 1.1 Children with endocrine conditions have access to a SPEC and regional clinical network in paediatric endocrinology |  |  |  |  | Service is compliant with NHS standard Contract Paediatric Medicine: Endocrinology and Diabetes, NSF guidelines. | Quality review of patient notes/correspondence.Formalised links between lead specialist centre and network centres. |
| 1.2 Children with endocrine conditions are managed at the appropriate location. This includes access to outreach clinics |  |  |  |  | Evidence of outreach clinics in the regional network. | Availability of outreach service.Anonymised patient list in outreach clinic. |
| 1.3 Plans are made for every child requiring review by a member of the SPEC team in one of the following ways:* immediate in-patient transfer to a SPEC
* outpatient/day case appointment at a SPEC or outreach clinic at the network centre.
* referral to another SPEC
* assessment in a condition-specific MDT
* a named consultant at the SPEC is identified to co-ordinate care
 |  |  |  |  | Job planning.Waiting list times for outpatients, day case investigation, inpatient investigation.Availability of condition-specific MDTs at lead specialist centre e.g. disorder of sex development MDT12,14. | Annual appraisal of job plan with appropriate time allowed for service delivery. |
| 1.4 Referrals to the SPEC are triaged and responded to within 5 working days. |  |  |  |  | Referral times. | Compliance with local waiting list/referral time standards.Examples of communication (e.g. letters, e-mail). |
| 1.4.1 Non-urgent clinical communication is sent to the child’s GP or referring healthcare professional within 5 working days. |  |  |  |  |
| 1.4.2 For less urgent advice, a member of the SPEC team provides an email or telephone response within 3 working days. |  |  |  |  |
| 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. |  |  |  |  |
| 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. |  |  |  |  |
| 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. |  |  |  |  |  | Examples of open access plans.Designated paediatrician at network centre. |
| 1.5 Shared care protocols are in place for investigations, diagnosis and management of endocrine disorders. |  |  |  |  | Adherence to any current published condition-specific guideline e.g. congenital hypothyroidism ESPE consensus 201411 | Evidence of updated and defined clinical pathways and local guidelines.Audit of individual conditions e.g. time to commence levothyroxine in congenital hypothyroidism patients.Evidence of shared care protocols. |
| 1.5.1 Shared care protocols and care pathways are in place to support immediate treatment in an emergency situation |  |  |  |  |
| 1.6 Telephone access to specialist consultant paediatric endocrine advice at the SPEC is available 24 hours a day. |  |  |  |  | On call rota | Availability of on call rota |
| 1.6.1 Telephone access to SPEC consultant advice is available to staff in secondary and tertiary care within the regional clinical network. |  |  |  |  |
| 1.6.2 Telephone advice outside normal working hours should be from the acute general paediatric or tertiary consultant to the consultant paediatric endocrinologist at the SPEC (consultant to consultant). |  |  |  |  |
| 1.6.3 Children, their families and health professionals have access to clear instructions and consultant/ specialist nurse advice during routine working hours at the SPEC. |  |  |  |  | Complaints about service | Patient satisfaction surveyRegistered complaints. |
| 1.6.4 Children who are under the care of the SPEC and their families, have access, outside working hours, to advice and emergency care from local on-call services |  |  |  |  | Anonymised high level incidents and action points | Audit of emergency admissions of children and young people with endocrine disorders |
| 1.7 A transition pathway is in place for all young people with endocrine disorders to transfer to adult services. |  |  |  |  | Any patient in transition from paediatric to adult care should have a defined and agreed plan for handover of care.Evidence of generic Transition pathways detailing Transition process.Transition/ Adolescent and Young Adult clinics. | Rapid quality review of patients’ notes |
| 1.8 Children with a gynaecological endocrine condition have the opportunity to be seen by a gynaecologist with an interest in paediatric and adolescent gynaecology. |  |  |  |  | Availability of specialist gynaecological services for children and young people.Designated lead for paediatric and adolescent gynaecology at the Lead specialist centre. | Patient satisfaction survey.Rapid quality review of patients’ notes. |
| 1.9 Access to imaging: |  |  |  |  |  |  |
| Urgent MRI at the SPEC or network centre (for non-neurosurgical emergencies) is available and discussed with a paediatric radiologist within 24 hrs. |  |  |  |  | Number of patients receiving investigation within the time frame.Time taken from investigation to reporting. | Notes audit/patient feedback, radiology audit trail. |
| non urgent MRI scans (including those under general anaesthetic) are available and reported by a paediatric radiologist within 8 weeks. |  |  |  |  |
| pelvic ultra-sound is available and reported by a radiologist within 12 weeks. |  |  |  |  |
| radiology services for bone age is available whenever a child attends their hospital appointment. |  |  |  |  |
| isotope scanning is available at SPEC. |  |  |  |  |
| dual energy x-ray absorptiometry (DXA) is undertaken in centres with expertise in bone densitometry in children, scans are reported within 12 weeks and a lead clinician is identified to link with medical physics for DXA. |  |  |  |  |

### 3.1.1 Composite summary of SPEC performance for Domain 1: Access to Specialised Paediatric Endocrine Services

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| **Peer Review team to complete** |
| **Standard** | **Exc** | **Met** | **UnM** | **NA** |
| **1.1** | [ ]  | [ ]  | [ ]  | [ ]  |
| **1.2** | [ ]  | [ ]  | [ ]  | [ ]  |
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| **1.9** | [ ]  | [ ]  | [ ]  | [ ]  |
| **Total** |  |  |  |  |

## 3.2 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** | **3a. Centre Self-assessment**Underline the Grade and add comments where appropriate | **3b. Assessment by Peer Review Team**Underline the Grade and add comments where appropriate | **Metric**From UK Paediatric Endocrine Standards 2019 | **Measurement method**From UK Paediatric Endocrine Standards 2019 |
| 2.1 There is a fully resourced multi-disciplinary team at the SPEC with a capacity for outreach clinics. |  |  |  |  | A multi-disciplinary team outlined in Appendix 1 is available.Job plans. | Manpower survey.Peer review.Local and regional Audit. |
| 2.1.1 There should be one WTE consultant paediatric endocrinologist at the SPEC per 500,000 population covered by the regional clinical network. |  |  |  |  | Consensus | Analysis of job plan against workload |
| 2.1.2 There should be 1.0 WTE Paediatric Endocrine Nurse Specialist at the SPEC per 750,000 population covered by the regional clinical network. Paediatric endocrine nurses should be a minimum AfC band 6 with at least 1.0 WTE band 7 at the SPEC. |  |  |  |  | ConsensusRCN recommendations. | Review specialist nurse appraisals for evidence of learning and active participation in team MDT |
| 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. |  |  |  |  |  | Evidence of access to education and attendance at national conferences. |
| 2.1.4 Paediatric endocrine nurse specialists will have an active role in clinics, outreach clinics, MDT meetings, service review and development. |  |  |  |  |  | Evidence of nurse led clinics.Attendance at clinics. |
| 2.1.5 The SPEC is supported by secretarial staff and database support to deliver service requirements and registry data entry. |  |  |  |  |  | Administration time available. |
| 2.1.6 The clinic booking rules (clinic template) for a general paediatric endocrine (4 hour) clinic at the SPEC or outreach clinic will be 1-2 new patients and 6-8 follow up appointments. |  |  |  |  |  | Anonymised clinic lists. |
| 2.1.7 The clinic template for condition-specific clinics or specialised MDT clinics at the SPEC will be variable and specific to the condition. |  |  |  |  |  | Anonymised clinic lists of specific clinics. |
| 2.2 The network centre is resourced to provide the local element of specialised endocrine care in partnership with the SPEC. |  |  |  |  |  | Agreed and up to date shared care guidelines. |
| 2.3 A 10 PA job plan for a consultant paediatric endocrinologist should include:* DCC allocation for clinics and separate DCC allocation for the patient administration that comes from each clinic.
* DCC allocation for chronic patient management between clinic visits and liaising with network centres.
* DCC allocation for each of: MDTs, inpatient management, supervision of day case investigations.
* DCC allocation for on call telephone advice.
* DCC/SPA allocation for attendance at network meetings (regional and national).
* DCC allocation for travel to outreach clinics.
* DCC allocation for safeguarding.
* 0.25-0.5 SPA allocation for endocrine service and regional network development.
* SPA allocation for revalidation, CPD, committee membership, etc.
 |  |  |  |  | Job planning | Job planning revews. |
| 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 SPEC and regional clinical network in paediatric endocrinology. |  |  |  |  | Job plans | Evidence of formal links, DCC allocation to DGH lead. |
| 2.3.2 Paediatricians at network centres have defined sessions in their job plan committed to outreach clinics and the regional clinical network in paediatric endocrinology, including network meetings.  |  |  |  |  |  |  |
| 2.4 The SPEC has co-location with other specialist services. |  |  |  |  | NHS Standard Contract Paediatric Medicine: Endocrinology and Diabetes1 | Patient satisfaction survey |
| 2.5 Specialist biochemistry facilities are available at the SPEC. Some network centres will also have these facilities. |  |  |  |  | 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. |
| 2.6 Facilities are available at SPEC and network centres to provide radiological investigations and expert interpretation. (see 1.9) |  |  |  |  | See 1.9 | See 1.9 |
| 2.7 There are shared care protocols for children requiring treatment with specialist endocrine drugs. |  |  |  |  | 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. |
| 2.8 Children requiring treatment with specialist endocrine drugs are funded/supported by shared care protocols. |  |  |  |  | Funding is in keeping with NICE guidelines where available.Use of BSPED approved shared care protocols. | Local audit against NICE guidance.Evidence of use of shared care protocols. |
| 2.9 There are allocated IT and administrative services to enable rapid transmission of clinical information across the network. |  |  |  |  | Patient database/Electronic Patient Record (EPR).Hospital IT systems with intranet and internet access. | Audit of letter times to referring HCP and/or information to parents. |
| 2.9.1 A patient database is resourced at the SPEC. |  |  |  |  |  | Evidence of use of patient database for condition-specific service evaluation, audit, collaboration, research |
| 2.9.2 There are allocated IT resources at the SPEC for participation in virtual MDT’s. |  |  |  |  |  |
| 2.10 Workforce planning mechanisms are in place to allow for year on year growth and service development dependent on a local needs assessment. |  |  |  |  | Success rate for business plans for service development.Service activity. | Service expansion. |
| 2.11 All Trusts guarantee continuity of the multidisciplinary team with timely succession planning. |  |  |  |  | Monitoring of service activity to justify expansion and/or continuity and succession planning. |
| 2.12 In all units providing care for children with endocrine conditions, staffing is planned to allow for:* study time
* attendance at MDT meetings
* CPD
* Annual leave
* Maternity leave
* sickness
 |  |  |  |  | Study leave allocation.Annual leave allocation | Annual appraisal and CPD certification. |
| 2.13 In all units, administrative support is provided for a managed clinical network. |  |  |  |  |  | Designated administrative support for MCN. |
| 2.14 In all areas involved in the care of children with endocrine disorders there is appropriate access to nurses trained in the care of children. |  |  |  |  | Compliance with the RCN competency framework. | Review of nurse job plans to ensure adequate cover. |
| 2.15 All clinical areas providing care for children with endocrine disorders have appropriate paediatric formularies. |  |  |  |  | Availability of paediatric formularies. | Availability of paediatric formularies which are up to date. |
| 2.16 Play specialists are employed in all appropriate areas of the service. |  |  |  |  | Availability of play specialists within departments. | Employment register. |
| 2.17 A child psychologist is available within the service. |  |  |  |  | Access to CAMHS. | Availability of CAMHS. |
| 2.18 Equipment, complying with national standards, is in place to meet the requirements of each:* service for measuring
* length/height
* sitting height
* weight
 |  |  |  |  | Equipment standards.Existence of appropriate auxological equipment | Regular monitoring of equipment accuracy and reliability. Availability of equipment. |
| 2.18.1 Electronic growth charts should be available. |  |  |  |  |  | Electronic charts available in EPR. |
| 2.19 Resources are available to support parent/family training. |  |  |  |  | Availability of education resources to support patient/family training. | Audit and patient satisfaction questionnaire. |
| 2.20 Facilities for parents are available on site at all inpatient settings. These include:* Overnight accommodation.
* Sitting room.
* Quiet room/area for private conversation.
* Facilities for making refreshments.
* Telephone.
* Access to networking with other parents.
 |  |  |  |  | Adherence to national standard. | Availability of facilities.Patient satisfaction questionnaire. |
| 2.21 Any child requiring dynamic hormone function testing should have been assessed by the paediatrician at the network centre or by the consultant paediatric endocrinologist at the SPEC. |  |  |  |  |  | Dynamic function test guidelines. |
| 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 and with immediate access to support from other healthcare professionals if required. |  |  |  |  |  |
| 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. |  |  |  |  |  |
| 2.24 The clinical area for day case investigations must allow for maintaining the child and family's dignity and privacy |  |  |  |  |  |

### 3.2.1 Composite summary of SPEC performance for Domain 2: Resources of Specialised Paediatric Endocrine Services

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| Peer Review team to complete |
| Standard | Exc | Met | UnM | NA |
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| 2.21 | [ ]  | [ ]  | [ ]  | [ ]  |
| 2.22 | [ ]  | [ ]  | [ ]  | [ ]  |
| 2.23 | [ ]  | [ ]  | [ ]  | [ ]  |
| 2.24 | [ ]  | [ ]  | [ ]  | [ ]  |
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## 3.3 Domain 3: Environment and facilities, care of the child and family 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.

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| **Standard** | **3a. Centre Self-assessment**Underline the Grade and add comments where appropriate | **3b. Assessment by Peer Review Team**Underline the Grade and add comments where appropriate | **Metric**From UK Paediatric Endocrine Standards 2019 | **Measurement method**From UK Paediatric Endocrine Standards 2019 |
| 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. |  |  |  |  | Service delivered according to UN convention guidance. | Adherence to guidance/Evidence of deviation. |
| 3.2 Children and their families are aware of the options available in their management in order to make an informed choice. |  |  |  |  | Evidence of availability of choices. | Audit of services.Patient satisfaction questionnaire. |
| 3.3 Facilities for day case investigations for endocrine disorders are available at the SPEC.  |  |  |  |  | Availability of day case facilities. | Existence and audit of facilities. |
| 3.4 Parent/carers are actively encouraged to participate in care.  |  |  |  |  | Availability of educational packs for patients and families. | Audit of written information provided to patients and their families.Patient/parent satisfaction questionnaire. |
| 3.5 Information and training is available for children and their families about services, their condition and care. |  |  |  |  |
| 3.6 Information and training is provided for children 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 care for a child, consideration is given to their practical needs, including regular breaks for personal needs, to obtain food/drink, make telephone calls. |  |  |  |  | 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 the SPEC.  |  |  |  |  | Documented evidence of links with support groups.Availability of information within the outpatient clinic. | Patient satisfaction questionnaire.Availability of written patient information.Audit of available information and service evaluation survey. |
| 3.9 Information is available for children and their families in several formats about their condition including leaflets/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, parents and families. |  |  |  |  |
| 3.12 Transition pathways are in place to allow for seamless transition to adult services  |  |  |  |  | Any patient in transition from paediatric to adult care should have a defined and agreed plan for handover of care.  | Evidence of MDT, audit of Transition process, compliance with NICE transition guidance and Trust transition standards. |
| 3.13 The needs of adolescents are recognised and met, including age appropriate inpatient and outpatient facilities.  |  |  |  |  | Provision of appropriate outpatient and inpatient facilities for adolescents. | Evidence of appropriate facilities.  |
| 3.14 Consent protocols are in place based on local/national recommendations. |  |  |  |  | Usage of national guidelines.Trust policy for consent. | Audit of consent for procedures.  |
| 3.15 In the case of the death of a child, protocols are in place to ensure information is cascaded to link paediatricians, general practitioners and all members of the MDT involved in their care.  |  |  |  |  | Documentation of protocols Agreed trust policy. | Trust Policy availableAudit of mortality and morbidity. |
| 3.16 When children 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 and their family and is recorded in their care plan.  |  |  |  |  | Existence of key worker for children with complex disorders. | Audit of services.Family feedback.Patient satisfaction questionnaire.Review of examples of outpatient appointment bookings. |
| 3.17 All children have access to ongoing educational opportunities whilst an inpatient.  |  |  |  |  | Access to schooling during inpatient visits. | Trust policy Audit.Evidence of school teacher in wards. |
| 3.18 Appropriate consent to physical examination and treatment is obtained for all children and chaperoning is available where necessary. |  |  |  |  | Compliance with the national guidance on consent. | Chaperone policy.Patient satisfaction questionnaire. Complaints. |

### 3.3.1 Composite summary of SPEC performance for Domain 3: Environment and facilities, care of child and family experience

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| Peer Review team to complete |
| Standard | Exc | Met | UnM | NA |
| 3.1 | [ ]  | [ ]  | [ ]  | [ ]  |
| 3.2 | [ ]  | [ ]  | [ ]  | [ ]  |
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| 3.18 | [ ]  | [ ]  | [ ]  | [ ]  |
| Total |  |  |  |  |

## 3.4 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.

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| **Standard** | **3a. Centre Self-assessment**Underline the Grade and add comments where appropriate | **3b. Assessment by Peer Review Team**Underline the Grade and add comments where appropriate | **Metric**From UK Paediatric Endocrine Standards 2019 | **Measurement method**From UK Paediatric Endocrine Standards 2019 |
| 4.1 There is clear and robust, effective, two-way communication between specialist services and primary and secondary care, network centres and the SPEC. |  |  |  |  | Appropriate IT systems are in place.Discharge summaries. | Audit of case notes.Evidence of correspondence within regional networks.Serious safety incidents relating to communication. |
| 4.2 Access to information systems including the child’s shared electronic healthcare record. |  |  |  |  | Appropriate IT systems are in place. |  |
| 4.3 SPEC and network centres maintain a database of patients. |  |  |  |  | Patient databases. | Evidence of database. |
| 4.4 Children and their families are encouraged to contribute to a patient satisfaction process. |  |  |  |  |  | Patient satisfaction questionnaire. |
| 4.5 Appropriate levels of communication exist between health professionals and children and their families e.g. evidence of contact telephone numbers or, email addresses, to enable children/parents/carers to make enquiries between appointments. |  |  |  |  | Evidence of contact details being communicated to families | Numbers of service complaints relating to clinical communication.Patient satisfaction questionnaire. |

### 3.4.1 Composite summary of SPEC performance for Domain 4: Communication

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| --- |
| Peer Review team to complete |
| Standard | Exc | Met | UnM | NA |
| 4.1 | [ ]  | [ ]  | [ ]  | [ ]  |
| 4.2 | [ ]  | [ ]  | [ ]  | [ ]  |
| 4.3 | [ ]  | [ ]  | [ ]  | [ ]  |
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| 4.5 | [ ]  | [ ]  | [ ]  | [ ]  |
| Total |  |  |  |  |

## 3.5 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** | **3a. Centre Self-assessment**Underline the Grade and add comments where appropriate | **3b. Assessment by Peer Review Team**Underline the Grade and add comments where appropriate | **Metric**From UK Paediatric Endocrine Standards 2019 | **Measurement method**From UK Paediatric Endocrine Standards 2019 |
| 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 CPD, and have protected time and funding to allow them to do this. |  |  |  |  | CCT in paediatric endocrinology or equivalent.CPD certificates.Comparison with BSPED and ESPE guidelines.Appendix 1 and 4 competencies. | Registration with an appropriate body for monitoring CPD.Adherence to guidelines/ RCPCH CSAC approval.Annual Appraisal documentation and Revalidation. |
| 5.2 All paediatricians and specialist nurses caring for children with endocrine disorders should be familiar with local safeguarding procedures. |  |  |  |  | National Safeguarding training policy. | Adherence to Safeguarding training.Adherence to Appendix 1 and 4 requirements. |
| 5.3 SPEC are accredited training centres3 (appendix 1 and 4 of the UK standards) |  |  |  |  | Approved accreditation. |  |
| 5.4 An induction programme is in place for all new members of staff. |  |  |  |  | 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. |  |  |  |  | Agreed training programme. | Evidence of attendance at training programme. |
| 5.6 As part of the regional clinical network, clinical pathways, protocols and guidelines are developed for the care and management of children with specific endocrine disorders. |  |  |  |  | Up to date clinical care pathways.Minutes of regional clinical network meeting demonstrating organisation of governance within network. | Annual MCN reports.Evidence of network functionality through network projects, minutes of organisational meetings and recording of protocol variance |
| 5.7 Audit programmes are organised within the regional clinical networks arrangements and include audit of:* Training
* Practice
* Compliance with pathways and protocols

Agreed outcomes |  |  |  |  | Departmental audits. | Availability of audit/reports and documentation of changes made. |
| 5.8 The SPEC and network centres will participate in BSPED peer review. |  |  |  |  | BSPED peer review. | Evidence of peer review participation. |
| 5.9 The SPEC and network centres will participate in national audit |  |  |  |  | Departmental audits. | Availability of audit/reports and documentation of changes made. |
| 5.10 All members of the regional clinical network have documented evidence of administrative and managerial support from the relevant Trusts and SPEC covering legal and ethical bases for clinical decision making. |  |  |  |  | Minutes of regional clinical network meeting and attendee/circulation list | Service evaluation.Network minutes and attendance information.Use of agreed MCN care pathways. |
| 5.11 Each regional clinical network produces an annual clinical governance report. |  |  |  |  | Network governance. | Annual MCN report. |
| 5.12 Paediatric endocrine nurses should be educated to degree level with expectation to work towards Masters level for career progression. |  |  |  |  |  | Evidence of career progression of nurses. |
| 5.13 Paediatric endocrine nurses should be working towards achieving ‘expert practitioner’ level. |  |  |  |  |  | Evidence of progress. |
| 5.14 Paediatric endocrine nurses should be a member of the BSPED and attend the annual BSPED meeting |  |  |  |  |  | Evidence of BSPED membership and attendance at BSPED meetings. |

### 3.5.1 Composite summary of SPEC performance for Domain 5: Clinical governance, Professional education and training, and Evidence base

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| Peer Review team to complete |
| Standard | Exc | Met | UnM | NA |
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| 5.14 | [ ]  | [ ]  | [ ]  | [ ]  |
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# Section 4. CONCLUSIONS AND RECOMMENDATIONS BY PEER REVIEW TEAM

This sections will be completed by the Peer Review team during and after the site visit based on all information gathered.

|  |  |  |
| --- | --- | --- |
|  |  | To be completed by Peer Review team |
| 1 | Actions and developments at the SPEC since the last BSPED Peer Review |  |
| 2 | Major Strengths of the Endocrine Unit and examples of good practice |  |
| 3 | Recommendations for SPEC based on self- and peer-assessment for the following domains: |
|  | Domain 1.Access to SPEC |  |
|  | Domain 2.Resources of SPEC |  |
|  | Domain 3.Environment and facilities, care of the child and family experience |  |
|  | Domain 4.Communication |  |
|  | Domain 5.Clinical Governance, Professional education and training, and Evidence base |  |

# Section 5. ACTION PLAN BY SPEC FOR RECOMMENDATIONS PROVIDED FROM THE PEER REVIEW

This section will be completed by the centre Lead on behalf of their centre, after the Peer Review. This will be shared with the BSPED within 2 months of the site visit.

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| --- | --- | --- | --- | --- | --- |
|  | Recommendation | Action required | Priority level:*High**Medium**Low* | Date for achievement | Responsible Lead |
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| 2 |  |  |  |  |  |
| 3 |  |  |  |  |  |
| 4 |  |  |  |  |  |
| 5 |  |  |  |  |  |

1. 1 Full-time consultant per 500,000 regional network population [↑](#footnote-ref-1)
2. 1 Full-time specialist nurse per 750,000 regional network population [↑](#footnote-ref-2)