NHS Wales Health Collaborative

Service Specification

Specialised Endocrinology Services for Adults

May 2022

Version 1

Document information	
Document purpose	Service Specification
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Description	NHS Wales Local Health Boards will routinely commission this tertiary service in accordance with the criteria described in this policy
Review Date	TBC

Revision History

Revision Date	Summary of Changes	Version
29/04/2022	Added section on BSUHB in section 1.6 Additions to Other Documents in section 1.8 Amendments made in section 2 on treatments offered and details of conditions Added to Aftercare objectives in section 2.1 and referrals in 2.3 Added to MDT details, Genetic Testing, Medication, Treatment in 2.4	0.2
3/5/2022	Added section on endocrinologist definition on page 13, and a section on radio iodine therapy on page 17.	0.3
06/05/2022	Added volumes in Service description 2.4	0.3
09/05/2022	Inserted section on endocrinopathies as an adverse effect of the treatment of cancer in section 2 Amended BCUHB section 1.6	0.3
10/05/2022	1.5, 1.6, 2.0 added further detail Updated section on reproductive conditions and endocrinopathies as an adverse effect of the treatment of cancer in section 2	0.4
11/05/2022	Amended Surgery in 2.4, and Quality Indicators 3.1 Amended section on BCUHB 1.6 Added WHSSC policies on Gender Services, added BritSPAG document and dates and links to documents.	0.6 0.6 0.6
12/05/22	Removed paragraph under section 2.4 MDT as new section inserted under 2.4 section on surgery.	0.7
18/05/2022	Moved paragraph on endocrinopathies from service delivery to section 2.7 interdependencies Moved paragraph from section 2.2 access criteria to section 2. Service delivery Inserted section on HDUHB	0.8
20/05/2022	Reviewed section 1.6 (including service is managed by consultant chemical pathologist) and section 2.7, adding pathology. Added points on Section 2.1 (treatment), 2.4 (surgery) and 4.2 (key performance indicators Added Adrenal Surgeon to MDT Amended Figures under Surgery Amended Quality and Patient Safety Amended Quality Indicators (3.1) Amended the following:	0.9

	1.4, 1.6, 1.8, 2, 2.1 (service aim/treatment), 2.4 Amended Genetic Testing section	
23/05/2022	Additional text on transition Additional references on minimum volumes	0.92
23/05/2022	Removed section on Hywel Dda, and condensed IPFR	0.93
24/05/2022	Formatting	0.94
21/07/2022	Made amendments following wider consultation – see notes	0.95

Approvals

This document requires the following approvals.

Group/Organisation	Date	Version
T&F Group	28/07/22	v0.95
NHS Wales Collaborative Executive Group	21/02/23	v0.95

Contents

Statement

This document has been developed to inform the commissioning of Specialised Endocrinology Services for adults in Wales.

In creating this document, the NHS Wales Health Collaborative has reviewed the requirements and standards of care that are expected to deliver this service.

Disclaimer

The NHS Wales Health Collaborative assume that healthcare professionals will use their clinical judgment, knowledge and expertise when deciding whether it is appropriate to apply this specification.

This policy may not be clinically appropriate for use in all situations and does not override the responsibility of healthcare professionals to make decisions appropriate to the circumstances of the individual patient, in consultation with the patient and/or their carer or guardian, or Local Authority.

The NHS Wales Health Collaborative disclaim any responsibility for damages arising out of the use or non-use of this specification.

1. Introduction

This document has been developed as the recommended service specification to inform the delivery and commissioning of Specialised Endocrinology Services for Adults resident in Wales.

Whilst the responsibility for commissioning Specialised Paediatric Endocrinology Services has been delegated to WHSSC, the responsibility for commissioning the Adult Specialised Endocrinology Services has been retained by the Health Boards, with the exception of some specialist elements being provided by WHSCC including pituitary surgery undertaken by neurosurgeons, specialised service for Neuroendocrine Tumours and Peptide Receptor Radionuclide Therapy (PRRT) for the Treatment of Neuroendocrine Tumours (NETs).

The service specification describes the scope of care provided by Adult Specialised Endocrinology Services. These services provide specialised medical, surgical and/or interventional radiological treatment for adolescents and adults with agreed endocrine disease.

1.1 Plain Language Summary

Specialised Endocrinology Services for Adults applies to the diagnosis and management of adults with rare conditions, including disorders of the thyroid, adrenal, neuro-endocrine (pituitary) axes, sex development and reproduction, hyperinsulinism, calcium/bone metabolism and endocrine cancer predisposition syndromes.

1.2 Aims and objectives

The aim of this service specification is to define the essential requirements and standard of care that providers are required to meet in order to deliver Specialised Endocrinology Services for Adults resident in Wales.

The objectives of this service specification are to:

- ensure that the commissioning of Adult Specialised Endocrinology Services is evidence based
- detail the specifications required to deliver Adult Specialised Endocrinology Services
- specify the minimum standards of care for the delivery of Adult Specialised Endocrinology Services
- ensure equitable access to Specialised Endocrinology Services for Welsh adults irrespective of geographical location
- identify the minimum requirements that services must meet in order to provide services for Welsh adults

- improve outcomes for adults with endocrine conditions who require specialised surgery

1.3 Background

Endocrine glands secrete hormones directly into the blood stream. The main endocrine glands are the pituitary gland, thyroid gland, pancreas, ovaries, testes and adrenal glands. Endocrinology is an area of medicine dealing with the endocrine system. It can be described as the study and treatment of diseases related to hormones.

Many endocrine conditions may be treated in local hospitals, but patients with complex or co-morbid conditions may require referral to specialised centres for consultant opinion or further management.

Specialised centres have dedicated multi-professional teams with experience in managing patients with multisystem, complex needs who often require specialist laboratory-based testing and imaging, combined with medical and surgical management.

Specialised conditions include patients presenting with specialised thyroid conditions, specialised pituitary/ hypothalamic conditions, neuro-endocrine tumours, familial endocrine conditions and reproductive conditions. A proportion of patients will require surgical intervention (e.g. hyperparathyroidism, Graves' disease, thyroid cancer and adrenal tumours).

Specialised Endocrinology services involve a large number of health care professionals including; consultant endocrinologists, consultant endocrine surgeons, consultant pathologists, consultant radiologists, consultant clinical geneticists, genetic counsellors, clinical scientists, consultant clinical and medical oncologists, endocrine biochemists, allied health professionals and clinical nurse specialists.

This service specification is for those centres where adults with specialised endocrine conditions are diagnosed and managed.

1.4 Population Covered

This service specification is aimed at delivering safe and effective care for patients 16 years old and over with a confirmed or suspected specialised endocrine condition, regardless of sex, race, or gender. Children 0-16 years of age are reviewed in the tertiary paediatric endocrinology service funded by WHSSC[1]. Children 16 years and older with endocrine conditions needing long term care into their adult life as per this service specification

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[1] WHSSC Service Specification, CP163 - Paediatric Endocrinology

will be referred from paediatric endocrinology to this service for specialist input.

Services will require staff to attend mandatory training on equality and diversity and the facilities provided offer appropriate disabled access for patients and carers. When required, the services will use translators and printed information available in multiple languages.

Services have a duty to co-operate with the commissioner in undertaking Equality Impact Assessments as a requirement of race, gender, sexual orientation, and religion and disability equality legislation.

1.5 Incidence Rate

- Pituitary and hypothalamic disease is 10 per 10,000 population;
- Differentiated thyroid cancer is 4 per 100,000 population, medullary thyroid cancer is 0.5 per 100,000 population;
- Primary hyperparathyroidism incidence rate is 30 per 100,000 population;
- Adrenal disease: Adrenocortical carcinoma is one per million population; Phaeochromocytoma is 2-8 per million population; Adrenal adenoma causing Cushing’s Syndrome is one per million population;
- Neuro-endocrine tumours: Carcinoid syndrome is 1 and gastrointestinal pancreatic neuroendocrine tumours is three per 100,000 population;
- Reproductive and gonadal endocrinology (disorders of sexual development) is 50 per 100,000 population;
- Complex calcium handling and metabolic bone diseases is ~ 5 per 100,000 per population;
- Familial endocrine disorders - Multiple endocrine neoplasia Type 1, Type 2 a or b rate of 1-3 per 100,000, Von Hippel Lindau disease rate of 3 and neurofibromatosis rate of 30 per 100,000 population, Phaeochromocytoma and Paraganglioma (PPGL) syndromes which have an incidence of ~2-8 per million.

1.6 Providers of Adult Specialised Endocrinology Services

All of the Health Boards in South and West Wales (with the exception of Powys THB) provide secondary care services for patients with endocrine conditions.

The following section details the providers of Specialised Endocrinology Services for Adults resident in Wales. The lists of services for each provider only describe those elements of service provision which are specialised, and are not representative of the full range of services that they provide, or of the full range of conditions that they manage.

Cardiff and Vale UHB

The service receives referrals from Aneurin Bevan UHB, Cardiff and Vale UHB, Cwm Taf Morgannwg UHB, and Powys THB. It also receives referrals from Swansea Bay UHB and Hywel Dda UHB for patients requiring specialised endocrine management. It provides medical and surgical management of the following conditions:

- Specialised thyroid conditions (including all thyroid malignancy and a joint thyroid eye clinic)
- Specialised calcium/bone conditions
- Specialised reproductive conditions
- Pituitary and hypothalamic diseases (including all surgery for pituitary disease in S Wales)
- Adrenal disease (including adrenocortical carcinoma)
- Neuroendocrine tumours of the gut and elsewhere
- Familial endocrine disorders (including surveillance for endocrine neoplasia)
- Rare lipid disorders

Swansea Bay UHB

The service receives referrals from Hywel Dda UHB, Swansea Bay UHB, and Powys THB. It provides medical and surgical management of the following conditions:

- Medical management of pituitary conditions
- Specialised thyroid conditions
- Specialised calcium/bone conditions
- Adrenal disease
- Familial endocrine disorders (including surveillance for endocrine neoplasia)
- Specialised reproductive conditions
- Rare lipid disorders
- Transition and young adult clinics

Patients in North Wales with pituitary and adrenal disorders, and neuroendocrine tumours requiring specialist services and/or surgery, are referred to Liverpool:

Walton Hospital NHS Foundation Trust

- Multi-disciplinary clinics for Pituitary Specialist Service including surgery

Royal Liverpool University NHS Foundation Trust

- Multi-disciplinary clinics for Adrenal Disorders including Adrenocortical carcinoma and Phaeochromocytoma and Neuroendocrine Tumours

In each organisation services are delivered by consultant endocrinologists, consultant endocrine surgeons, consultant pathologists, consultant radiologists, consultant clinical and medical oncologists, endocrine biochemists and clinical nurse specialists.

Genetic counselling and genomic testing for Welsh patients is provided by the All Wales Medical Genomics Service (AWMGS).

Rare lipid disorders are managed by the specialised lipid service. This service is delivered by Consultant Chemical Pathologists, and does not form part of the specialised endocrinology service.

1.7 Relationship with other documents

This document should be read in conjunction with the following documents:

WHSSC Service Specification

- CP163 - Paediatric Endocrinology (2019) CP163 - Paediatric Endocrinology
- CP67 - Peptide Receptor Radionuclide Therapy (PRRT) for the Treatment of Neuroendocrine Tumours (NETs) (2016) CP67 - Peptide Receptor Radionuclide Therapy (PRRT) for the Treatment of Neuroendocrine Tumours (NETs)
- CP182a – Gender Identity Service for Adults (Non-Surgical) (2020) CP182a - Gender Identity Service for Adults (Non-Surgical)
- CP182b – Gender Identity Service for Adults (Non-Surgical) (2020) CP182b - Gender Identity Service for Adults (Non-Surgical)
- CP50a – Positron Emission Tomography (PET) CP50a Positron Emission Tomography (PET)
- Genomics Service Specification Genomics Service Specification (CP99)

NHS Wales

- All Wales Policy: Making Decisions on Individual Patient Funding (2016) Making Decisions on Individual Patient Funding Requests (IPFR)
- A Healthier Wales - our Plan for Health and Social Care (2018) A Healthier Wales - Our Plan for Health and Social Care
- National clinical framework: a learning health and care system (2021) National Clinical Framework: A Learning Health and Care System
- Transition and Handover of Care – Welsh Government Guidelines (2022) The Transition and Handover Guidance

Society for Endocrinology

- Defining the future for Endocrinology (draft report accessible at: https://www.endocrinology.org/clinical-practice/future-of-endocrinology-working-group/)

GIRFT 2020 (Getting it right first time)
- GIRFT Report (2021) GIRFT - Endocrinology Report

The Society of British Neurological Surgeons
- Recommendations for low volume pituitary surgery Jan 2018 (https://www.sbns.org.uk/index.php/policies-and-publications/)

ENETS European Neuroendocrine Tumor Society
- ENETS 2016 Consensus Guidelines Update for the Management of Functional p-NETs (F-p-NETs) and Non-Functional p-NETs (NF-p-NETs) (Falconi *et al*. 2016) Consensus Guidelines Update for the Management of Functional p-NETs (F-p-NETs) and Non-Functional p-NETs (NF-p-NETs)
- ENETS Standards of Care from 2017 Guidelines - enets.org

Relevant NHS England policies
- 2013/14 NHS Standard Contract for Specialised Endocrinology Services (Adult) NHS commissioning » A03. Specialised Endocrinology (england.nhs.uk)
- BritSPAG Clinical Standards for Service Planning in PAG (2011) Clinical Standards for Service Planning in PAG
- NHS England Rare and Inherited Disease Eligibility Criteria (2022) NHS England Rare and Inherited Disease Eligibility Criteria

1.8 National and international service guidance

The following are national and international guidance from which this service specification has been drawn.

NICE Guidance and Clinical Knowledge Summaries

- NICE technology appraisal guidance [TA64] Published: 27 August 2003. Human growth hormone (somatropin) in adults with growth hormone deficiency
- Transition from children's to adults' services for young people using health or social care services. NICE Guideline (NG43) 2016

Other Documents

- Royal College of Physicians management of thyroid conditions (2019) Thyroid Disease: Assessment and Management
- Guidelines for the management of adrenal disease

- European Society of Endocrinology Clinical Practice Guidelines on the Management of adrenocortical carcinoma in adults (Fassnacht, M *et al* 2018, European Journal of Endocrinology) Clinical Practice Guidelines on the Management of Adrenocortical Carcinoma in Adults

2. Service delivery

The aim of this service specification is to define the criteria that providers are required to meet in order to provide Specialised Adult Endocrinology Services for adolescents (new referrals of young people, aged 16 years and above) referrals of adolescents aged 16 years and above from paediatric endocrinology services with endocrine conditions, and adults with agreed endocrine disease resident in Wales. Health Boards will commission Specialised Endocrinology Services in accordance with the criteria outlined in this document.

The main diagnostic and monitoring methods include biochemistry (including dynamic endocrine function testing), genomic testing, cytology, histology, radiological investigations, ultrasound (US), bone densitometry, computerized tomography (CT)/magnetic resonance imaging (MR) (including radiologically-guided biopsy), functional nuclear medicine scans, endoscopic ultrasound, inferior petrosal sinus and adrenal venous sampling.

Treatments offered include medical, surgical and/or interventional radiological management of endocrine disease for adolescents (and their families) and adults. In addition, the service will offer education, nutritional, psychological support and counselling about endocrine disease and treatment, including for adolescents undergoing transition from paediatric to adult specialised endocrinology services.

Medical treatment is predominately delivered in an outpatient setting, endocrine surgery requires inpatient stay (most often 24 hours or more) and where appropriate in an inpatient (ward) or day unit with carefully monitored shared care arrangements in place with referring clinicians.

Specialised medical and surgical treatment will be provided for patients with one of the following conditions:

Specialised thyroid conditions; includes all thyroid malignancies (differentiated thyroid cancer, medullary thyroid cancer, thyroid lymphoma, anaplastic carcinoma), re-do thyroid surgery for benign or malignant disease, thyroid hormone resistance and MDT management of thyroid eye disease.

Calcium/bone conditions; includes complex calcium and phosphate handling conditions such as complex primary hyperparathyroidism (recurrent/with bone complications/localization issues/familial), osteogenesis imperfecta, familial hypocalciuric hypercalcaemia, x linked hypophosphataemia, skeletal dysplasias, hypoparathyroidism, Paget's disease of bone and complex parathyroid conditions in pregnancy.

Pituitary/hypothalamic conditions; includes all pituitary and hypothalamic conditions requiring specialised MDT review (including functioning pituitary adenomas causing Cushing's disease, Acromegaly, Thyrotropinoma (TSHoma), or refractory prolactinomas) and complex pituitary conditions in pregnancy.

Adrenal conditions; includes congenital adrenal hyperplasia, adrenal tumours requiring specialised adrenal MDT review (adrenal Cushing's syndrome, confirmed primary hyperaldosteronism, phaeochromocytoma and paraganglioma (PPGL), adrenocortical carcinoma), and complex adrenal conditions in pregnancy and bilateral adrenalectomy for ACTH-dependent Cushing's Syndrome.

Neuroendocrine tumours (NETs); includes functioning NETs causing carcinoid syndrome, insulinoma, gastrinoma, glucagonoma, VIPoma's and neuroendocrine tumours outside the gut (e.g. bronchial, thymic).

Inherited Endocrine Tumour Syndromes; includes multiple endocrine neoplasia Type 1 and Type 2, familial medullary thyroid carcinoma, Von Hippel Lindau syndrome, neurofibromatosis type 1, Carney complex and familial PPGL syndromes.

Reproductive Conditions; including Differences in Sex Development (DSD) such as congenital adrenal hyperplasia, androgen insensitivity syndrome, Turner syndrome, Mayer-Rokitansky-Küster-Hauser syndrome and 17-beta hydroxysteroid dehydrogenase III deficiency, primary amenorrhoea, and Fertility Tissue Cryopreservation Service (with links to the national service (Oxford)). This includes a service for patients needing vaginal dilation, psychological support and reproductive surgery.

Endocrinopathies as an adverse effect of the treatment of cancer; includes Immunotherapy-induced endocrinopathies and Endocrine late effects of cancer treatment with cytotoxic drugs and radiation therapy.

2.1 Service Aim and Objectives

The aim of the service is to provide patient centred specialist care for adolescents (new referrals of young people aged 16 years and above), adolescents aged 16 years and above referred from paediatric endocrinology service as part of the transition process and adults with agreed endocrine disease and promote their optimal future and quality of life.

Rarely, new referrals for adolescents aged 16 years and above with specific conditions which are perhaps best addressed in the paediatric endocrinology service may occur and this must be mutually discussed and agreed between this service and paediatric endocrinology service by the triaging clinician.

The overall objectives of the service are as follows:

Diagnosis objectives:

- Early identification of patients with complex multisystem disease, ensuring that they have timely access to specialised care for accurate diagnosis.
- Rapid access for new and existing patients in an emergency against best practice clinical protocols.
- Increase awareness of best practice in the diagnosis and management of these rare conditions through active engagement and shared care with local providers for a network approach.

Treatment objectives:

- Delivery of evidence-based treatment plans (or best practice treatment in rare disorders where limited evidence exists). This should lead to improved treatment outcomes (reduced mortality and co-morbidity) and maximisation of patients' functional ability through best practice multi-professional management strategies.
- Endocrine surgery should be delivered by high-volume surgeons, as described by the European Society of Endocrine Surgeons (ESES), British Association of Endocrine and Thyroid Surgeons (BAETS) and the GIRFT endocrinology report. These surgeons should be approved and active members of the regional MDT. Lateral lymph node surgery in thyroid cancer should be performed at specialist centres as recommended in the WCN 2018/19 peer review report
- Integration of patient care across departments within centres (e.g. between endocrinology, surgical and radiological services and A&E and inpatient wards) with audited standardised flagging protocols in place
- Consistent and equitable decision making about the use of off license therapies in refractory or relapsing disease
- Adolescents aged 16 years and above requiring transition to adult services from paediatric endocrinology service should have an integrated approach between the two services in joint paediatric and adult transition clinics. The transition service should take into account the overarching principles of transition care such as

involvement of young people and their carers in service design, delivery and evaluation related to transition and to ensure that the transition support is developmentally appropriate, taking into account the person's maturity, cognitive abilities and communication needs. The transition process should be strengths-based and focus on what is positive and possible for the young person rather than on a pre-determined set of transition options and use person-centred approaches to ensure that the transition support is provided in a holistic manner.

Aftercare objectives:

- Appropriate shared care arrangements using standardised shared-care protocols between specialities, with local and national services, for the management of comorbidities directly associated with the patient’s rare disease, delivered as close to patients’ homes as possible.
- Continuity of care in long-term follow up with access to specialised services being maintained.
- Detailed audit of patient outcomes / experience and the dissemination of best practice, including annual submission of surgical outcome data to the UK Registry of Endocrine and Thyroid Surgery (https://www.baets.org.uk/audit/). It is also proposed that some activity would form the basis of a national registry for some rare endocrine tumours and autoimmune disease.
- Discharge of patients to local follow-up once specialised endocrinology input complete (e.g., after surgical cure of functioning endocrine tumours) under agreed protocols.

2.2 Access criteria

This service is for adolescents (new referrals of young people aged 16 years and above) and adults with agreed specialised endocrine disease. Young adolescent patients aged 16-18 years who satisfy the acceptance criteria for the Paediatric Endocrinology Service should be discussed with the Paediatric Endocrinology MDT. Patients who do not have a rare endocrine condition that requires the expertise of a specialised endocrinology service are excluded.

2.3 Patient referrals

Referrals will be accepted by general endocrinologists, or through direct referral from General Practitioners where patients meet the definition of a specialised endocrine condition.

2.4 Service description

Services must achieve specific quality standards and measures. The provider must also meet the standards as set out below. **This will alter depending on sub speciality.**

The Multidisciplinary Team (MDT)

The core members of the Specialised Adult Endocrinology MDT are:

Essential	Desirable
Adult Endocrinologist Clinical nurse specialist from adult and paediatric endocrine services Paediatric Endocrinologist Endocrine and/or thyroid/parathyroid surgeon Adrenal Surgeon Pathologist with expertise in assessment of endocrine pathology Medical biochemist with expertise in endocrine testing and interpretation Clinical Genetics Team Radiologist, including expertise in functional imaging Nuclear Medicine expertise Interventional radiologist Gynaecologist with expertise in reproductive endocrinology (as required) Fertility specialist (as required) Oncologist (as required)	Other surgical specialty input on a case-by-case basis

MDT coordinator Specialist Pharmacist	

Care Pathway

The care pathways for patients are as follows:

Imaging and pathology

Imaging and pathology services must be available to the multi-professional group in line with the network agreed guidelines for these services. The pathology services should comply with Clinical Pathology Accreditation (UK) Ltd (CPA) and the Human Tissue Authority (HTA) and should complete the Royal College of Pathologists' minimum dataset.

Genomic testing and genetic counselling

The All Wales Medical Genomics Service (AWMGS) provides clinical and laboratory genomic services for the people of Wales, commissioned by the Welsh Health Specialised Services Committee. The clinical genetics team provide genetic counselling services for patients/families with a confirmed or suspected genetic diagnosis. This includes predictive testing for at-risk relatives, explaining reproductive options and communicating information about natural history, complications & surveillance for specific conditions. Given the diversity of the diseases seen by medical genomics, there is no generic pathway for access into / through the services.

The Adult Specialised Endocrine Services should have embedded clinical genetics and laboratory genetics services to provide genetic counselling and specialist genetic testing. This includes 'mainstreaming' (initiation of genomic testing by non-genetic health professionals), which will be supported by AWMGS laboratory and clinical teams.

Genetic testing, reporting, counselling and laboratory activity are required to be delivered in line with the standards set out in the WHSSC Genomic service (all ages) service specification (CP99).

For patients with a suspected genetic condition, Adult Specialised Endocrine Services will:

- Liaise with the AWMGS laboratory and/or clinical genetics team for advice if needed.
- Arrange appropriate genetic testing in line with the NHSE genomic test directory.

- Where appropriate, consent patients for genetic testing, explaining the possible limitations and results.
- Communicate the results of requested genetic tests to patients.
- Where appropriate, refer patients to the AWMGS Clinical Genetics team for genetic counselling to discuss a confirmed or suspected genetic diagnosis.

Medication

Medication to be prescribed and administrated against agreed best practice guidelines and national policy / guidelines for somatostatin analogues, pegvisomant, mitotane, cinacalcet, tolvaptan, teriparatide, burosumab, sunitinib and other tyrosine receptor kinase inhibitors, everolimus and other mammalian target of rapamycin (mTOR) inhibitors.

Surgery

Thyroid cancer and autoimmune disease surgery should be undertaken by high volume Units performing more than 50 thyroid operations per year [2]as this is associated with lower morbidity[3]. Parathyroid surgery should be undertaken in Units performing a minimum of 20 cases per year[4]. Adrenal surgery should be undertaken in Units performing more than 6 adrenal operations per year and adrenal cancer in Units performing at least 20 adrenal operations per year[5].

Similarly, minimal unit or surgeon-specific operative numbers by condition have been stated by both the British Association of Endocrine and Thyroid Surgeons (BAETS) and the recent GIRFT report relating to endocrinology.

Treatment

Specialised thyroid conditions (including all thyroid malignancy and a joint thyroid eye clinic)

- All thyroid cancer patients to be discussed at multidisciplinary team with review of imaging, cytopathology, histopathology and biochemical tests.
- Differentiated thyroid cancer: minimum of 10 years' follow-up then devolved to non-specialised endocrine service. Low/high dose ablative ^{131}I treatment. Ultrasound (US) neck and stimulated thyroglobulin (Tg) monitoring. Monitoring of thyroid function tests (TFT). Subsequent Tg monitoring. Iodine uptake scans, positron

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[2] Volume, outcomes, and quality standards in thyroid surgery: an evidence-based analysis-European Society of Endocrine Surgeons (ESES) positional statement, Lorenz et al, Langenbecks Arch Surg 2020 Jun;405(4):401-425

[3] A national analysis of trends, outcomes and volume-outcome relationships in thyroid surgery, Nouraei et al, Clin Otolaryngol 2017; 42(2):354-365

[4] Endocrinology GIRFT Programme National Specialty Report, 2021

[5] Endocrinology GIRFT Programme National Specialty Report, 2021

emission tomography-computed tomography (PET-CT), US and magnetic resonance imaging (MRI) as required. Suppressive T4 treatment according to risk stratification.

- Medullary thyroid cancer: urinary/plasma metanephrines prior to surgery, Lifelong follow-up in tertiary centre. Calcitonin monitoring. Imaging: US scanning, Nuclear Medicine investigations and/or PET-CT scanning, MRI, genetic testing.
- Lymphoma: refer to haematology multidisciplinary team.
- Total body irradiation with iodine (TKI) treatment for advanced/metastatic disease as required. Surgical treatment (subject to commissioning policy) may include:
- All thyroid cancer surgery including diagnostic hemithyroidectomy ± completion surgery total thyroidectomy, lymph node surgery (neck and rarely mediastinum), surgery for recurrent thyroid cancer and metastases, TKI treatment
- Radioiodine administration - Radioiodine therapy for benign thyroid disease is not considered a component of adult specialist endocrinology services. As such it is anticipated that Health Boards will ensure that they have individuals with the appropriate qualifications to deliver this service as a component of their local endocrinology capabilities and also that suitable arrangements are in place for the treatment to be deployed.

Specialised calcium/bone conditions

- Medical management - Outpatients assessment, multidisciplinary team review, scans, tests and medication to strengthen bones (teriparatide, denosumab). Follow-up in tertiary centre. Renal Ultrasound, DEXA scan, vertebral morphometry assessment, 24hr urine calcium, sestamibi, single photon emission CT (SPECTCT), US neck, 4D Computerised Tomography (CT), Magnetic Resonance Imaging, intraoperative parathyroid hormone sampling, prescribing and administrating cinacalcet, recombinant PTH and burosumab.
- Hearing assessment, dental assessment, intravenous (IV) bisphosphonates, denosumab, burosumab, genetic testing & counselling, vertebroplasty, kyphoplasty, occupational therapy, social worker, physiotherapy.
- Surgery includes parathyroid surgery, open parathyroidectomy, minimally-invasive parathyroidectomy, surgery for renal hyperparathyroidism, mediastinal surgery – first time operation and reoperative intervention, spinal corrective surgery, intramedullary rods and nails and other appropriate surgery outlined in agreed national clinical protocol.

Specialised reproductive conditions

- Outpatients assessment (endocrine).

- Multidisciplinary team review (endocrine, genetics, gynaecology, fertility) Imaging (ultrasound, CT, MRI, hysterosalpingogram, laparoscopy, DEXA scan).
- Endocrine assessment (urine and serum including sex steroids, pituitary hormones, adrenal function, tumour markers).
- Short synacthen tests, dexamethasone suppression tests.
- Genomic testing, which may include chromosomal analysis and/or gene panel testing, with appropriate referral to AWMGS.
- Fertility assessments (endocrine profiles, semen analysis).
- Medication (including sex steroid replacement, adrenal hormone replacement, emergency replacement regimens) Fertility treatments (including recombinant gonadotrophins and clomiphene/letrozole).
- Follow-up in tertiary centre.
- Surgery includes genital reconstructive surgery, surgical sperm retrieval and gonadectomy.
- Comprehensive service for vaginal dilatation

Pituitary and hypothalamic diseases

- Outpatient assessment, multidisciplinary team review, scans (pituitary and hypothalamus +/- gadolinium), tests (e.g.: inferior petrosal sinus sampling, insulin tolerance tests, glucose tolerance tests, synacthen tests, water deprivation tests, other dynamic tests to assess hypothalamic-pituitary function)
- Family cascade screening after genetic diagnosis (refer to Genetic Medical Services)
- Pituitary surgery (transsphenoidal and transcranial surgery. Endoscopic transsphenoidal / transnasal)
- Pituitary stereotactic radiation therapy. Patients are required to have counselling prior to treatment, with all the potential complications that can arise from irradiating the pituitary gland discussed. Stereotactic radiation therapy for pituitary disease is to be commissioned in dedicated pituitary clinics in a limited number of centres and consider where appropriate ‘single fraction’ radiotherapy. This is due to the challenges in planning treatment of pituitary disease and the risk of blindness. The treating team should include surgeons, nurse specialists, radiographers expert in stereotactic radiation therapy and physicists. (Service provision for this intervention is required to be delivered in line with the stereotactic radiotherapy service specification).

Adrenal disease (including adrenocortical carcinoma)

- Outpatients assessment, multidisciplinary team review, scans (MRI, CT, FDG-PET, Ga-PET CT), tests (adrenal vein sampling (AVS) by bilateral adrenal vein catheterisation, aldosterone and renin secretion), medication (steroids) and consideration for surgery.

- Adrenal radiology: CT, PET-CT, Ga-PET CT, MRI, MIBG, Octreotide scan.
- Adrenal pathology: Weiss score/Aubert score for adrenocortical carcinoma/adrenal incidentaloma, PASS score for phaeochromocytoma, advanced immunohistochemistry including SDH immunostaining.
- Mitotane and monitoring of mitotane concentrations.
- Chemotherapy: in addition to mitotane therapy in selected cases.
- Radiotherapy to be administrated by cancer multidisciplinary team. Surgery (subject to commissioning policy) may include:
- Adrenal surgery (laparoscopic adrenalectomy, open adrenalectomy sometimes in collaboration with other surgical specialties)

Neuroendocrine tumours of gut and elsewhere

- Outpatients assessment, multidisciplinary team review, scans (CT, MRI, ultrasound, endoscopic ultrasound, Octreotide scan, Gallium PET-CT), tests (urinary 5-hydroxyindoleacetic acid (5HIAA), fasting gut hormone profile, supervised inpatient fast), medication (Octreotide LAR, Lanreotide Autogel, everolimus, sunitinib), peptide receptor radionuclide therapy (PRRT), liver-directed therapies (e.g. hepatic artery embolization).
- Surgery (Hepatobiliary, thoracic).

Inherited Endocrine Tumour Syndromes (including surveillance for endocrine neoplasia)

- Screening (biochemical, radiological) and genomic testing. Watch-and-wait approach.
- Outpatient assessment, multidisciplinary team review, radiological scans, biochemical tests (fasting gut hormone profile, Calcium, parathyroid hormone (PTH), urine or plasma metanephrines) and medication.
- Family cascade predictive testing via AWMGS. Surveillance of asymptomatic mutation carriers with imaging, hormone profiling, urine or plasma metanepharines, timing of surgery.
- Surgery
- Treatment & follow up

Rare lipid disorders

2.5 Acceptance criteria

Referrals will usually be accepted from general endocrinologists or paediatric tertiary endocrinologists.

Once referred the patient will be assessed by an appropriate specialised endocrinology service.

The service outlined in this specification is for patients aged 16 years or over, ordinarily resident in Wales, or otherwise the commissioning responsibility of the NHS in Wales.

2.6 Transition across paediatric and adult services

The transition process for adolescents is a multifaceted active process that attends to the medical, psychosocial, educational, and vocational needs of adolescents as they move from child to adult centred care. NICE clinical guideline states transition should be developmentally appropriate and supportive while allowing young people and their carers to be involved in the process.

Continuity of care from paediatric to adult services should be ensured through a co-ordinated handover plan, with formal transition complete when a patient attends an adult clinic.

Providers should consider the recommendations within the NICE guidance on transition[6], and the Welsh Government transition and handover guidance[7], and associated quality standards to help children and young people and their carers have a better experience of transition and handover to adult's services by improving the way this is planned and carried out.

Providers must have a clear accountability and delivery mechanism in place, which includes identifying and designating a senior lead reporting to the Quality and Safety Committee, who will have accountability for ensuring implementation and quality of the transition and handover guidance across all primary, secondary, tertiary and community services. The senior lead will be responsible for championing transition and handover at a strategic level.

Transitions between paediatric and adult services should be planned, to ensure that they are continuous, seamless, timely and efficient. The child or young person with long term conditions commencing during childhood, must be offered choices about transition and handover of care at a point determined by their overall needs, including any national condition specific guidance.

Every child and young person transferring from children to adults' services will have a documented Transition and Handover Plan (THP), or equivalent.

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[6] Transition from children's to adults' services for young people using health or social care services (2016) NICE guideline NG43

[7] Welsh Government - The Transition and Handover Guidance (February 2022)

Clear communication between professionals is essential at these points. Services need to consider transition processes from long-term ongoing childhood care through to adult services. This transition needs to be actively managed and supported with enablers encouraged and obstacles removed. The manner in which this process is managed will vary on an individual case basis with multidisciplinary input often required and patient and family choice considered together with individual health board and environmental circumstances factored in.

Children and adult teams should work together to achieve continuity and the most effective services for the child or young person. If any clinician feels they are practicing outside their competence due to the age of the patient, they must escalate the matter through their scheme of clinical accountability.

2.7 Exclusion criteria

Patients under 16 years of age. Young adolescent patients aged 16-18 years who satisfy the acceptance criteria for the Paediatric Endocrinology Service should be discussed with the Paediatric Endocrinology MDT.

2.8 Interdependencies with other services or providers

It should be noted that there are a broad range of other specialised services that have important interfaces with specialised adult endocrinology services.

Services generally required access to: Oncology, Radiology, Medical Biochemistry, Endocrine CNSs with access to dynamic endocrine function testing, interventional radiology, other surgical disciplines where there is overlap (e.g. vascular surgery, cardiothoracic surgery, hepato-biliary surgery), genetics (both clinical and laboratory) and pathology.

Services generally required to be onsite: radiology, medical biochemistry, endocrine CNSs with access to dynamic endocrine function testing, interventional radiology, other surgical disciplines where there is overlap (e.g. vascular surgery, cardiothoracic surgery, hepato-biliary surgery), pathology and pharmacy.

Services which do not generally need to be on-site but to which rapid access is required: oncology, nuclear medicine/radiology (e.g. Ga-PET CT). Endocrinopathies, including premature ovarian insufficiency and subfertility, as adverse effects of the treatment of cancer. This is done within gynaecology services and requires a pathway from cancer services into long-term follow up, with an early years central service prior to eventual follow up closer to home.

Services with which there is a relationship but may not require to be onsite or have rapid access: supra-regional providers of biochemical tests (e.g. aldosterone, renin, gut hormones), clinic and laboratory genetics.

2.9 Continuation of Treatment

Healthcare professionals are expected to review a patient's health at regular intervals to ensure they are demonstrating an improvement to their health due to the treatment being given. If no improvement to a patient's health has been recorded, then clinical judgement on the continuation of treatment must be made by the treating healthcare professional.

2.10 Patient Pathway

This service is comprised of the following elements:

- Assessment, diagnosis and management of adolescents and adults with endocrinology disorders that fall within the scope of this specification as defined in section 2.
- Establishing and restoring a good equilibrium in patients as soon after diagnosis as possible by refining dosage, monitoring bloods, day curve analysis etc.
- Surgical treatment for patients with endocrine disorders of the thyroid, parathyroid, adrenal, pituitary, and endocrine pancreas.
- Provision of emergency, elective and planned care.
- Raising awareness among General Practitioners (GPs) and secondary care services on presentation of suspected endocrine conditions, with particular note to onset of life-threatening endocrine disorders to ensure timely diagnosis and treatment where appropriate.
- Crisis prevention/management of life-threatening complications that would typically occur in a non-endocrine setting, surgery or accident and emergency department. Service to develop and distribute patient information and best practice protocol to wider clinical staff/paramedics who may be required to manage an endocrine emergency.
- Long-term follow-up for patients with a chronic endocrine condition, where clinically appropriate and there is a clear evidence base, in the specialist service to enable better management and prevention of emergency situations.
- Education on self-management, counselling support and long-term follow up monitoring for patients with chronic endocrine conditions.
- Close working relationship with designated site-specific cancer services.
- Close working relationship with local endocrinology services to ensure as much care as possible is delivered closer to home.

Patients should continue to be supported and monitored by specialist centre in conjunction with local services as indicated.

- Advise primary care on management of condition, treatment plan and follow-up monitoring arrangements as required e.g., frequency of pituitary function test in hypopituitary patients.
- Provision of dedicated adolescent transition service to adult care.
- Individuals with confirmed inherited conditions and at-risk carrier relatives should be referred to clinical genetics, including specialised genetics services (e.g. VHL and access to prenatal genetics where relevant).

2.11 Exceptions

If the patient does not meet the criteria for treatment as outlined in the service specification, an Individual Patient Funding Request (IPFR) can be submitted for consideration in line with the All Wales Policy: Making Decisions on Individual Patient Funding Requests. The request will then be considered by the IPFR Panel of the Local Health Board in which the patient is resident.

3. Quality and patient safety

Services must work to written quality standards and provide monitoring information to commissioners. The quality management systems must be externally audited and accredited.

Services must enable the patients, carers and advocates to be informed of participation and be able to demonstrate this. Provision should be made for patients with communication difficulties.

With respect to the quality indicators described it is imperative that a structure is designed to allow for local audit in terms of mortality and morbidity meetings but in addition supra-regional and annual meetings should be convened.

For all HCPs this requirement must have adequate time allocated within individual and team job planning.

Each Health Board should provide annual figures relating to surgical inpatient volume and the areas in which this is performed. Figures should be provided per department and per surgeon.

Evidence regarding return to theatres and revision surgery should be provided and audited locally and nationally.

Any developing trends need to be identified, explored and discussed particularly if there is concern regarding potential detrimental outcomes.

Annual figures are required relating to the numbers waiting and the time to be seen for outpatient appointments and with whom these are performed. These need to be collated for routine new and urgent new appointments as well as FUNB.

Where possible a breakdown following triage in terms of whether these patients require a Consultant Endocrinologist review or alternate HCP review (e.g. extended scope practitioner) should be provided.

Endocrine surgeon appointments need to be audited.

Endocrine surgeon health care professional appointments need to be collated and audited with volume in each health board identified and accountability and responsibility to health care professionals also clearly identifiable.

Where non-specialised services are provided by generic health care professionals, this data also needs to be provided.

3.1 Quality indicators (standards)

The Specialised Endocrinology services are required to:

- Attend MDT meetings
- Hold quarterly specialty-specific mortality and morbidity meetings;
- Participate in annual quality assurance;
- Participate in collection and submission of data into appropriate databases
- Provide data to commissioners to support the assessment of compliance with the service specification.
- Undertake regular patient experience surveys, patient reported outcome measures and develop and implement an action plan based on findings
- Report the following Clinical outcomes:

Surgery:

Surgeons undertaking thyroid, parathyroid and/or adrenal surgery should enter their data into the United Kingdom Registry of Endocrine Surgery (UKRETS). To access UKRETS, surgeons will be members of BAETS and ensure that they maintain CPD. Data entered will include:

- Number (and outcome) of total thyroidectomies (cancer and non-cancer)
- Number (and outcome) of parathyroidectomies
- Number (and outcome) of adrenalectomies
- Mortality: in and out of hospital mortality (including cause of death). Comparison with published survival data.
- Post-operative morbidity: vocal cord palsy & hypocalcaemia after thyroidectomy, cure rates for hyperparathyroidism, open versus laparoscopic procedures for adrenal disease.

All:

- Remission and relapse rates: Using recognised disease-specific measures of disease activity.
- Disease-related damage: Using recognised disease-specific damage indices.
- Quality of life.
- Participation in clinical trials.
- Disease cure for patients with functioning endocrine tumours e.g. Phaeochromocytomas, Cushing’s Syndrome
- Pituitary
- Post-surgical morbidity.
- Quality of life in patients with Specialised Endocrine disease

- Pituitary surgery and NET outcomes are excluded from this document as this service is commissioned separately.

Report the following Process outcomes:

- Waiting times: Time to operation, time from referral to operation from hospital data systems.
- Post-operative morbidity length of stay, reoperation rates, readmission rates.
- At annual appraisal, the number of operations, success rates and complication rates should be assessed per surgeon and compared with national averages
- Patient / carer satisfaction: questionnaire survey.
- Access to support groups and education: questionnaire survey plus patient/ carer participation.
- Maintenance of Disease Registry: Rare Bone Disease registry (in development).
- Evidence of programme of joint working with non-specialised centres: Shared care protocols, outreach clinics.
- Contribution to surgical data registry (e.g. British Association of Endocrine & Thyroid Surgeons).
- Collection of standardized and coded activity and outcome data.
- Activity data should be collected in cases of i) Use of off-label drugs, and ii) Management of rare diseases

3.2 Other quality requirements

The Adult Specialised Endocrinology services will:

- Perform regular reviews of functionality and performance.
- Participate in condition-specific national UK audits, where available, in order to ensure the best possible clinical outcomes. All audits should consider the results of all surgeons in the centre
- Use a recognised system to demonstrate service quality and standards.
- Use detailed clinical protocols setting out nationally (and local where appropriate) recognised good practice for each treatment site.
- Ensure that the quality system and its treatment protocols will be subject to regular clinical and management audit.
- Hold other meetings regularly to address clinical, service delivery and governance issues.
- Review of risk registers and Welsh Risk Pool data

The above should form the basis of an annual report shared with Health Boards who refer to the service or participate in it.

It is the Provider’s responsibility to notify the commissioner on an exceptional basis should there be any breaches of the care standards. Where there are breaches any consequences will be deemed as being the Provider’s responsibility.

Services must comply with the relevant NICE quality standards which defines clinical best practice.

3.3 Patient experience

The provider will ensure that patients have access to the relevant support groups and education, and will conduct regular surveys of patient / carer satisfaction in line with national guidance.

4. Performance monitoring and information requirement

4.1 Performance monitoring

Health Boards will be responsible for commissioning services in line with this policy. This will include agreeing appropriate information and procedures to monitor the performance of organisations.

For the services defined in this policy the following approach will be adopted:

- Services to evidence quality and performance controls.
- Services to evidence compliance with standards of care.

4.2 Key performance indicators

The providers will be expected to monitor against the full list of Quality Indicators derived from the service description components described in Sections 3.1 and 3.2.

The provider should also monitor the appropriateness of referrals into the service and provide regular feedback to referrers on inappropriate referrals, identifying any trends or potential educational needs.

In particular, the provider will be expected to monitor against the following target outcomes:

- Equitable access (by LHB population) to surgery
- Surgery component waiting time for patients (day case and IPT)
- Number of cancelled operations leading to avoidable delay and negative patient experience
- Hospital stay by condition (median length of stay in days)
- Surgical complication rates and 28-day re-admission rates
- Regular submission of data via UKRETS National registry allowing unit benchmarking for operative KPIs and surgical volume
- Number of Serious Untoward Incidents (SUIs) reported
- Number of written complaints received
- Infection monitoring as per section 3.1
- Multidisciplinary mortality and morbidity meetings – documentation and evidence of learning

4.3 Date of review

This document is scheduled for review before 2023, when we will check if any new evidence is available.

If an update is carried out the policy will remain extant until the revised policy is published.

5. Equality impact and assessment

The Equality Impact Assessment (EQIA) process has been developed to help promote fair and equal treatment in the delivery of health services. It aims to enable Health Boards to identify and eliminate detrimental treatment caused by the adverse impact of health service policies upon groups and individuals for reasons of race, gender re- assignment, disability, sex, sexual orientation, age, religion and belief, marriage and civil partnership, pregnancy and maternity and language.

This policy will be subjected to an Equality Impact Assessment.

6. Putting things right: raising a concern

6.1 Raising a concern

Whilst every effort has been made to ensure that decisions made under this policy are robust and appropriate for the patient group, it is acknowledged that there may be occasions when the patient or their representative are not happy with decisions made or the treatment provided.

The patient or their representative should be guided by the clinician, or the member of NHS staff with whom the concern is raised, to the appropriate arrangements for management of their concern.

If a patient or their representative is unhappy with the care provided during the treatment or the clinical decision to withdraw treatment provided under this policy, the patient and/or their representative should be guided to the LHB for NHS Putting Things Right. For services provided outside NHS Wales the patient or their representative should be guided to the NHS Trust Concerns Procedure, with a copy of the concern being sent to provider Health Board.

6.2 Individual patient funding request (IPFR)

If the patient does not meet the criteria for treatment as outlined in the service specification, an Individual Patient Funding Request (IPFR) can be submitted for consideration in line with the All Wales Policy: Making Decisions on Individual Patient Funding Requests. The request will then be considered by the IPFR Panel of the Local Health Board in which the patient is resident.

If an IPFR is declined by the Panel, a patient and/or their NHS clinician has the right to request information about how the decision was reached. If the patient and their NHS clinician feel the process has not been followed in accordance with the policy, arrangements can be made for an independent review of the process to be undertaken. The grounds for the review, which are detailed in the All Wales Policy: Making Decisions on Individual Patient Funding Requests (IPFR), must be clearly stated.

If the patient wishes to be referred to a provider outside of the agreed pathway, an IPFR should be submitted to the Local Health Board in which the patient is resident.