GETTING IT RIGHT FIRST TIME

Endocrinology

GIRFT Programme National Specialty Report

Professor John Wass and Mark Lansdown
GIRFT clinical lead for endocrinology and GIRFT clinical ambassador

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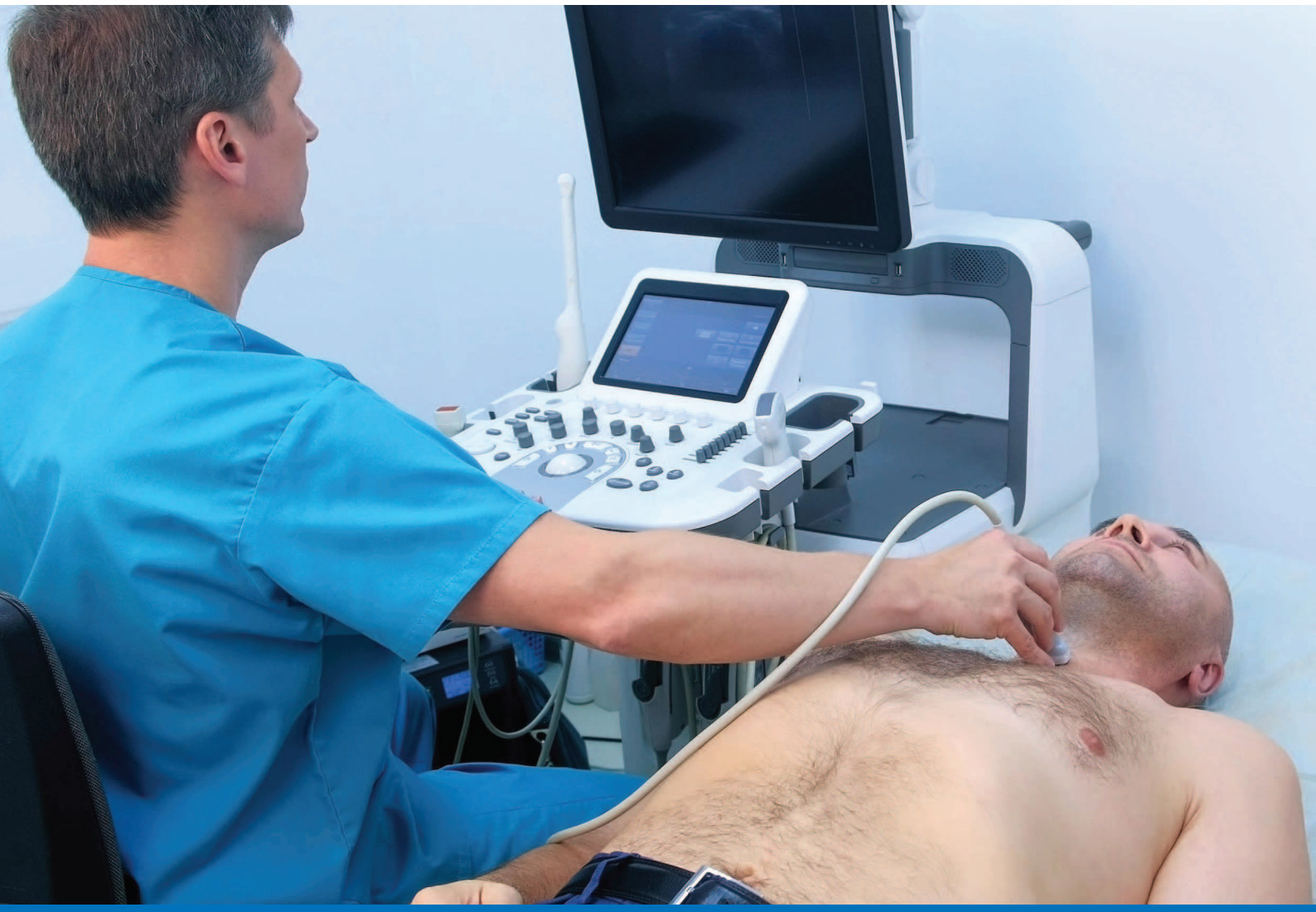

GIRFT is delivered in partnership with the Royal National Orthopaedic Hospital NHS Trust, NHS England and NHS Improvement

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Foreword from Professor Tim Briggs GIRFT Programme Chair

I am delighted to recommend this Getting It Right First Time review of endocrinology, led by Professor John Wass.

This report comes at a time when the NHS has undergone profound changes in response to the COVID-19 pandemic. The unprecedented events of 2020 – and the extraordinary response from everyone working in the NHS – add greater significance to GIRFT's recommendations, giving many of them a new sense of urgency.

Actions in this report, such as running outpatient services more efficiently by making better use of pre-testing and remote appointments, can help the NHS as it faces the substantial challenge of recovering services, while remaining ready for any future surges, by operating more effectively and safely than ever before.

Professor Wass has applied the GIRFT approach to his field, a growing specialty that covers some of the most common conditions as well as some of the rarest. Endocrinology sits at the intersections of different types and settings of care: medical and surgical, primary and secondary and overlapping between other specialties.

This distinctive specialty presents some interesting challenges, such as ensuring that patients' diagnoses, treatment and care are provided at the appropriate level and by a clinician or surgeon who has the relevant expertise and experience, and that endocrinology activity and outcomes are recorded and audited.

The recommendations set out in this report are based on Professor Wass' visits to 126 trusts, in addition to other data, audits and a detailed survey of trusts. Implementing these 17 recommendations will optimise pathways for our patients and our use of clinical time, reduce low volume operating, implement much needed tier 3 obesity services across the country and support continued innovation in the specialty.

One thing that was clear from all of Professor Wass' visits was that staff were working very hard to provide excellent endocrinology services to patients. I am most heartened to hear how supportive people have been as he has been carrying out his review.

It is crucial to recognise this excellence and collaborative spirit. GIRFT cannot succeed without the backing of clinicians, managers and all of us involved in delivering care.

My greatest hope is that GIRFT will provide further impetus for all those involved in endocrinology, in different disciplines, settings and specialties, to work shoulder to shoulder to deliver solutions and improvements that will improve the experience and outcomes for patients.

Professor Tim Briggs *CBE*

GIRFT Programme Chair and National Director of Clinical Improvement for the NHS.

Professor Tim Briggs is a consultant orthopaedic surgeon at the Royal National Orthopaedic Hospital NHS Trust, where he is also Director of Strategy and External Affairs. He led the first review of orthopaedic surgery that became the pilot for the GIRFT programme, which he now chairs. Professor Briggs is also National Director of Clinical Improvement for the NHS.

Introduction

Endocrinology is an exciting, important and growing specialty encompassing both common and extremely rare conditions, some of which require complex management. In 2018/19 there were 626,686 recorded endocrinology adult outpatient attendances and this number is growing year by year. Thus in the last five years endocrine outpatient activity has increased by 31% excluding diabetes and obesity, over and above general medical outpatient activity, which increased by 17.5%. Often significant delays in diagnosis occur but the opportunity is there to make huge differences to people's quality and quantity of life, e.g. with timely treatment for Addison's disease and thyroid disease and we can help achieve pregnancy in infertile couples, a truly life changing effect on a patient's life.

Endocrinology continues to rapidly advance, producing huge amounts of research that are contributing to our increased knowledge from this country and around the world.

The GIRFT programme has provided an invaluable opportunity to look across the breadth of our specialty and ask searching questions about variations in current practice and to reflect on and share examples of innovation and best practice in the many places where we found them. One thing that was clear in our visits throughout England was that all the staff in endocrinology were working very hard, often in difficult circumstances, to provide excellent services to patients.

Our aim has been to see how best endocrinology can manage a broad range of conditions through multidisciplinary team working. This means ensuring that patients are offered care at the most appropriate level and are dealt with by professionals, both physicians and, where necessary, surgeons, with significant experience in treating their condition.

Surgery plays an important role in the treatment of a proportion of patients with endocrine disorders. For some conditions it is the best available treatment and for others it will be a matter of patient choice. Patients, and the endocrinologists who refer them for surgery, need to have confidence in the surgical team and know their outcomes and complication rates. Surgeons should have the appropriate skills and knowledge to carry out their work, ensuring they do not act outside their competence.[1] The rational way for surgeons to demonstrate that they have achieved good outcomes for endocrine patients is through audit. However, at some visits we found surgeons who did not submit their data for audit. This goes against the best practice set out by the General Medical Council (GMC), which states that all surgeons must contribute to audit. The document Good Surgical Practice[2] explains how the GMC guidance should be interpreted. Surgeons are expected to submit all activity data to national audits and databases relevant to their practice and present the results at appraisal for review against the national benchmarks.

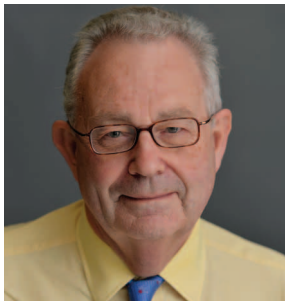
Hospital Episode Statistics (HES) data was not originally developed for clinical audit but, never the less, analysis of this information shows substantial variation in some outcomes and lengths of stay. Variation of outcomes is also seen in the national audit, the United Kingdom Register of Endocrine and Thyroid Surgery (UKRETS). The opportunity provided by the GIRFT programme for sharing best practice will, we believe, lead to an improvement in quality of care and outcomes for patients undergoing endocrine surgery.

Recognition of endocrinology in hospital coding systems is far from perfect. Indeed, some hospitals (including one university teaching hospital) have no documented endocrine cases, despite the fact that the clinicians are very busy with such cases. This needs to be rectified urgently; it not only affects the visibility of the specialty as a whole, but has a detrimental effect on income for these hospitals.

As the health needs of the population change, so does the provision required, and we have identified an urgent need for obesity services at least at Tier 3 level in hospitals across the country. Currently this is the case in only 44% of the hospitals we visited. This is a challenge for endocrinology and one we have addressed in our recommendations.

We now must make sure that the recommendations are achieved and we have carefully set out how and by when this should happen.

We thank all those stakeholders who have been involved in this process and offered their insights. We, and they, are optimistic about the future of our specialty.



Professor John Wass

Clinical Lead, Professor of Endocrinology, Oxford University and Former Chair of the Clinical Reference Group for Endocrinology in the UK

Mark Lansdown

Consultant Endocrine Surgeon, Former President BAETS and GIRFT Clinical Ambassador

[1] *General Medical Council (GMC) (2019), Good medical practice, paragraphs 14 and 66, www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/good-medical-practice*

[2] *Royal College of Surgeons (2014), Good surgical practice, https://www.rcseng.ac.uk/standards-and-research/gsp/*

Statements of support

Society for Endocrinology

The Society for Endocrinology welcomes and endorses this endocrinology report from the GIRFT programme. The report has highlighted that patient pathways must be better optimised with streamlined referral and follow-up processes. It has described that data quality and collection is a weakness which compromises safety and effectiveness. The report has emphasised the crucial role of endocrine nurses and support staff in maintaining patient-centred service efficiencies.

These findings are consistent with evidence we have seen through our own Interdepartmental Peer Review scheme, and are issues that have been discussed and addressed at our committees. This report will support better consistency of endocrine care across NHS trusts, and the process itself has already prompted a drive to improve clinical practice in endocrinology.

The report is timely; the COVID-19 pandemic has severely disrupted endocrinology services and as we reintroduce services we now have a great opportunity to reinvent the practice of our specialty. Our accelerated learning over the past few months will enable us to support the endocrine community to effectively implement the recommendations from GIRFT to improve endocrinology services for the benefit of our patients.

Professor Stephanie Baldeweg
Clinical Committee Chair, Society for Endocrinology

Professor Rajesh Thakker
FRS FMedSci
President, Society for Endocrinology

Society for Endocrinology

Royal College of Surgeons of England

The surgery for endocrine diseases straddles a number of specialties including ENT, transplant surgery, neurosurgery, urology and within the former specialty of general surgery dedicated endocrine and hepatobiliary surgeons. The volume of endocrine surgery in each NHS trust is small and within each of these specialisms even smaller. When this is the case it is difficult to have meaningful audits and reduce variation in techniques and management towards best practice and a reduction in complications. The optimal outcomes for our patients will result from the concentration of medical and surgical endocrinology into specialist multidisciplinary teams. All patients having endocrine surgery should be registered in the national UKRETS database, allowing the proper analysis of large patient cohorts.

I welcome the GIRFT programme specialty report on endocrinology and particularly support the recommendations for improving surgery in this fascinating and often challenging group of patients.

Professor Neil Mortensen
President, Royal College of Surgeons of England

Royal College of Surgeons
ADVANCING SURGICAL CARE

Executive summary

Our GIRFT review of endocrinology has found a significant degree of unwarranted variation in a number of key areas. After further investigation and analysis there appear to be several important opportunities to improve patient care and outcomes in endocrinology along with a notional financial opportunity of between £5.5m and £9m a year.

Getting it Right First Time (GIRFT)

The GIRFT programme is funded by the Department of Health and Social Care and jointly overseen by NHS Improvement and the Royal National Orthopaedic Hospital NHS Trust.

GIRFT seeks to identify variation within NHS care and then learn from that variation. It is one of several workstreams designed to improve operational efficiency in NHS hospitals. In particular, it is part of the response to Lord Carter's review of productivity, and is providing vital input to the Model Hospital project.

GIRFT is closely aligned with other programmes seeking to improve standards while delivering efficiencies, such as NHS RightCare, acute care collaborations (ACCs) and sustainability and transformation partnerships (STPs)/integrated care systems.

Under the GIRFT programme, data from many NHS sources is consolidated and analysed to provide a detailed national picture of the specialty being reviewed. This process highlights variations in care decisions, patient outcomes, costs and other factors. The data is then reviewed by a GIRFT clinical lead for the specialty – an experienced clinician who is recognised as an expert in their specialty.

The clinical leads visit each individual hospital trust to discuss the data with senior management and clinical teams. These deep-dive visits provide an opportunity for both parties to learn. The individual trusts are able to understand where their performance appears to be below average and can draw on clinical expertise to identify actions targeted at addressing performance issues. At the same time, the clinical lead builds a national picture of best practice that feeds into service-wide improvement recommendations and an implementation programme to drive change and address unwarranted variation.

Endocrinology today

Endocrinology is a relatively small but rapidly growing specialty covering a range of conditions that affect or originate in the body's endocrine system. Some of these are relatively easily managed while others require medical treatment and/or surgery, which may be complex and/or urgent in some cases. The overlap between endocrinology and other specialties means surgical procedures may be carried out by surgeons from a range of clinical backgrounds.

The specialty is characterised by a significant amount of outpatient work, including long-term follow-up for several conditions.

About our analysis

We identified 126 trusts providing endocrinology services, each of which we supplied with a data pack and visited for a 'deep dive'. We also made copious use of additional data, both from a questionnaire sent to each of the 126 trusts and from various additional sources, as cited throughout this report. While paediatric services were not specifically examined in our deep dives or the data, we feel the recommendations in this report can still be considered and applied within paediatric endocrinology, ensuring it is well-evidenced.

What we found

Where we found unwarranted variation we investigated this and applied data analysis to examine the situation in detail wherever possible. We grouped our findings and subsequent recommendations under the headings that follow.

Optimising patient pathways

Streamlined pathways are at the heart of good patient care and yet there is a wide range of anomalies at present, which may undermine this. Poor delineation between the roles of primary and secondary care means diagnostic tests are being duplicated unnecessarily, causing delays and uncertainty. Unclear definitions around what constitutes specialised care can also cause delays and exacerbates funding issues. Hub and spoke and networked care provision should be the dominant service model for specialist care, but this is not currently the case in all trusts. Patients with life-threatening non-cancer endocrine conditions are being delayed while non-life threatening cancer conditions are prioritised. Lengths of stay for the

same procedure vary to a degree that goes beyond what we feel is acceptable. This is detrimental to patients, who would rather be at home, and prevents trusts from freeing up beds.

Ensuring endocrinologists and surgeons record and know their numbers, outcomes and complication rates

Effective audit and the availability of data thus attained is key to ensuring safe and effective care; an unaudited service can provide no assurance that it is either safe or effective. This is particularly pertinent when it comes to recording the complications arising from surgery, which can be life changing for patients with serious endocrine conditions. There is currently an unacceptably low rate (53%) of surgeons entering data on the 'mandatory' UKRETS audit. There is also a lack of clarity around known complications of endocrine surgery and the protocols associated with them.

Concentrating key procedures among fewer surgeons to avoid low volumes

There is a growing body of knowledge to support the theory that low-volume surgery is more likely to result in outcomes that are less successful and less safe. For the more common procedures, patients should be treated by surgeons who perform these operations regularly. Where surgery is for rare or complex conditions, the case is even more compelling. Our investigations revealed unwarranted variation in the individual surgeon volumes considered acceptable for endocrine procedures. Based on the information available, it seems irrefutable that, in order to ensure the best outcomes for patients, trusts should work collaboratively and/or in networks to ensure that patients requiring complex or rarely performed surgical procedures are directed only to surgeons with appropriate training and experience.

Innovations in endocrinology

Effective management of referrals, waiting lists and, in particular, follow-up appointments is vital to ensuring endocrinology continues to grow without placing undue strain on patients, the endocrine workforce or trusts as a whole. We noted in particular scope to improve triage and pre-investigation for outpatient referrals and the management of follow-up appointments.

Workforce

It is vitally important, particularly for a growing specialty, that the workforce is structured around the needs of patients. Where this is not the case, for whatever reason, quality of care suffers. Endocrinology relies on highly trained multidisciplinary teams (MDTs) and it is important that clinicians' time is freed up to care for patients. We noted in particular a high degree of variation in the number of trained endocrine specialist nurses available within trusts, who provide not only clinical expertise but leadership, as well as other staff who can offer crucial support to clinicians and registered nurses running clinics, thus increasing efficiency and quality of care.

Implementing Tier 3 obesity services

Obesity is, as is well established, an increasingly important marker of healthcare needs and comes with a significant number of complications. It is also a growing problem across the nation. Currently only 44% of trusts provide obesity services at Tier 3 level (specialist non-surgical and multidisciplinary) or above to care for these patients, many of whom have significant co-morbidities. In agreement with the clinical leads for the GIRFT diabetes report, we recognise this as a situation requiring urgent action.

Improving data quality and data collection

We noted during our analysis that inconsistent or absent coding for endocrinology activity is not unusual, with the result that the specialty is underrepresented in the data of many trusts. This is due in part to historical anomalies and in part simply to poor communication between clinicians and coders. It is also the case that there is, in many trusts, only a vague delineation between coding for outpatient and day case endocrine activity.

Litigation

There is some evidence that litigation claims could not be defended effectively because providers lacked the necessary documentation. It was also interesting that many providers had little knowledge of the claims against them. We recommend that providers employ GIRFT's five-point plan to help reduce litigation costs.

Making it happen – GIRFT regional support

Our report makes 17 recommendations and identifies owners and timelines for each one.

GIRFT regional teams support providers in implementing the recommendations.

They provide practical advice based on the research data, feedback from visits and expert input of experienced clinicians.

Recommendations and actions

Recommendation	Actions	Owners	Timescale
1. Reduce unnecessary duplication of diagnostic tests to streamline initial referral and avoid wastage. Appropriate information sharing is an essential part of the provision of safe and effective care.	**a** GIRFT and the Society for Endocrinology to provide guidance on which diagnostic tests are appropriate to be carried out or commissioned by GPs prior to referral to secondary or specialist care, and which should follow or be conducted at an initial outpatient visit or arranged between referrer and referee.	GIRFT, Society for Endocrinology	12 months
	b GIRFT to ensure guidelines on diagnostic testing at appropriate point in patient journey inform Choose and Book criteria.	GIRFT	12 months
	c In line with new NHS Digital's Data and Technology Standards Framework, providers should look to improve digital interoperability to enable clearer visibility in both directions on the electronic patient record around which tests have been conducted/ requested, as well as any which follow after diagnosis and treatment.	Trusts	2 years
2. Expedite prompt referral to specialised care where indicated (in this recommendation we support the work of the NHS Neuroscience Transformation Programme and the work currently being undertaken by NHS England to rewrite the specification for specialised adult endocrinology services).	**a** GIRFT to ensure proposed list of endocrine conditions which indicate a need for specialised care are fed into NHS England review of specifications for specialised endocrinology services.	GIRFT	6 months
	b Trusts to declare compliance with service specifications for treating these conditions through the Quality Surveillance Information System (QSIS).	Trusts	For immediate action
	c Trusts to agree referral and repatriation criteria and record these consistently to ensure that referrals between centres include a clear rationale for the need for specialist input in a standardised way.	Trusts	12 months
3. Deliver networked service models so that patients can be referred to the most appropriate surgeon and the correct level of care.	**a** Trusts to establish service-level agreements to facilitate and deliver recommended network service arrangements and models (see recommendation 8) including for: i. treatment of medullary thyroid cancer; ii. adrenalectomies (and to ensure within each network there is a hub for adrenal cancer and phaeochromocytomas); iii. pituitary surgery.	Trusts	For substantial progress within 1 year
4. Consider options to accelerate urgent treatment for patients with serious non-cancer endocrine conditions.	**a** GIRFT to work closely with NHS England and trusts to review referral pathways for life-threatening endocrine conditions or conditions which have risks of major complications (listed below) to ensure that patients can access urgent treatment without unnecessary delay once diagnosis is confirmed: i. phaeochromocytoma; ii. severe hypercalcaemia; iii. severe pressure symptoms of enlarged thyroid; iv. Cushing's syndrome; v. severe Graves' disease.	GIRFT, NHS England	12 months

Recommendation	Actions	Owners	Timescale
5. Ensure that where clinically appropriate, lengths of stay for surgical procedures are reduced.	**a** Trusts to review their patient pathways with a view to achieving the following targets for elective admissions:[3] i. 90% of patients having parathyroid surgery for primary hyperparathyroidism to be discharged with zero night stay (day case); ii. 90% of patients undergoing thyroid lobectomy to be discharged with no more than one night's stay; iii. 90% of patients undergoing total thyroidectomy to be discharged with no more than two nights' stay.	Trusts	For immediate consideration and action within 6 months
6. Improve audit and availability of data relating to all endocrine operations.	**a** All surgeons carrying out thyroid surgery, as well as those carrying out parathyroid or adrenal surgery should participate in the British Association of Endocrine and Thyroid Surgeons (BAETS) electronic UK Registry of Endocrine and Thyroid Surgery (UKRETS) to allow for accurate auditing of services.	Trusts, BAETS	For immediate action
	b Trusts to include data capture for national audit as part of job descriptions and job planning for consultants, with time allocated as required.	Trusts	Immediate and ongoing
7. Agree clearer definitions and protocols for surgical complications.	**a** GIRFT to work with patient groups and professional societies to review and agree clearer definitions of surgical complications e.g. deficient calcium post thyroidectomy, damage to the recurrent laryngeal nerve post-thyroidectomy and hypopituitarism post hypophysectomy (removal of the pituitary gland).	GIRFT	6 months
	b GIRFT to work with professional societies to share exemplar protocols for conditions where surgery involves a known risk of life-changing complications or post-operative issues, e.g. thyroid bleed protocols.	GIRFT	12 months
8. Trusts should work collaboratively in networks or amalgamate services to concentrate surgical expertise. Direct patients requiring surgery to appropriately trained surgeons performing the recommended volume of procedures.	**a** Optimise specialist endocrinology care and ensure a safe service is provided, as recommended in national service specifications and international guidelines. In particular: i. Centres carrying out very few **adrenalectomies** (under six adrenalectomies per surgeon per year or under 20 if they are operating on patients with adrenal cancer and phaeochromocytoma) should stop doing so. These centres should refer patients to surgeons within their network who perform this procedure at higher volumes. ii. Centres carrying out **thyroid surgery** should ensure surgeons are carrying out a minimum number of 20 thyroid operations each per annum or that patients are being referred to surgeons within their network who perform these procedures at higher volumes. iii. Centres carrying out **parathyroid surgery** should ensure surgeons are operating on at least 20 patients per annum or that their patients are being referred to surgeons within their network who perform these procedures at higher volumes.	Trusts, STPs	1 year to develop networks Immediate Immediate Immediate

[3] *See Appendix 3 for a table summarising BADS-recommended lengths of stay for the procedures listed.*

Recommendation	Actions	Owners	Timescale
8. (continued) Trusts should work collaboratively in networks or amalgamate services to concentrate surgical expertise. Direct patients requiring surgery to appropriately trained surgeons performing the recommended volume of procedures.	**a** iv. Centres carrying out **pituitary surgery** should ensure surgeons are operating on 20 patients per annum, aspiring to 50 operations per department per year or their patients should be referred to surgeons within their network who perform these procedures at higher volumes.	Trusts, STPs	Immediate
	b Endocrinology departments should work with regional vascular and radiology networks to optimise numbers regionally and improve success rates of adrenal venous sampling (AVS) and petrosal sinus sampling.	Trusts	6 months
	c GIRFT to work with the NHS pricing team to ensure that commissioning models encourage best practice by only funding adrenalectomies and pituitary surgery where these are carried out at a specialist centre.	GIRFT, NHS pricing team	12 months
9. Review appropriate triage and pre-investigation for outpatient referrals to improve patient flow, address capacity challenges and enable innovative practice.	**a** Trusts to review current protocols around pre-investigation diagnostic blood/urine tests prior to first outpatient appointment, to enable between 30-50% of patients to be pre-investigated and triaged.	Trusts	6 months
	b Trusts, with input from the Society for Endocrinology, to develop protocols for the implementation of clinical/referral assessment services to support appropriate triage of outpatient referrals and increase the likelihood of discharge at first appointment.	Trusts, Society for Endocrinology	12 months
10. Review management of follow-up appointments.	**a** Society for Endocrinology to develop follow-up protocols to ensure that endocrinology departments can benchmark performance against approved pathways for each endocrine condition.	Society for Endocrinology	12 months
	b GIRFT to work with the National Outpatient Transformation Programme to look at increasing availability of remote appointments/virtual clinics, especially for follow-ups.	GIRFT, NOTP	6 months
	c Trusts to explore options to advance to a core level of digitisation by 2024, as set out in the NHS Long Term Plan.	Trusts	12 months
	d GIRFT to work with the NHS pricing team and the National Outpatient Transformation Programme to review current pricing arrangements and incentives for video versus telephone appointments.	GIRFT, NHS pricing team, NOTP	6 months
11. Ensure all surgeons and wider team members involved in endocrine activity have access to the latest information and training to maintain their competence.	**a** GIRFT and Joint Committee on Surgical Training (working with the specialty and subspecialty Specialist Advisory Committees) to jointly produce a cross-specialty endocrine surgery module for pre- or post-certificate training.	GIRFT, JCST, SAC	12 months
	b Trusts should endeavour to facilitate and support endocrinology-specific training for the wider endocrinology team, including Society for Endocrinology training for nurses.	Trusts	12 months

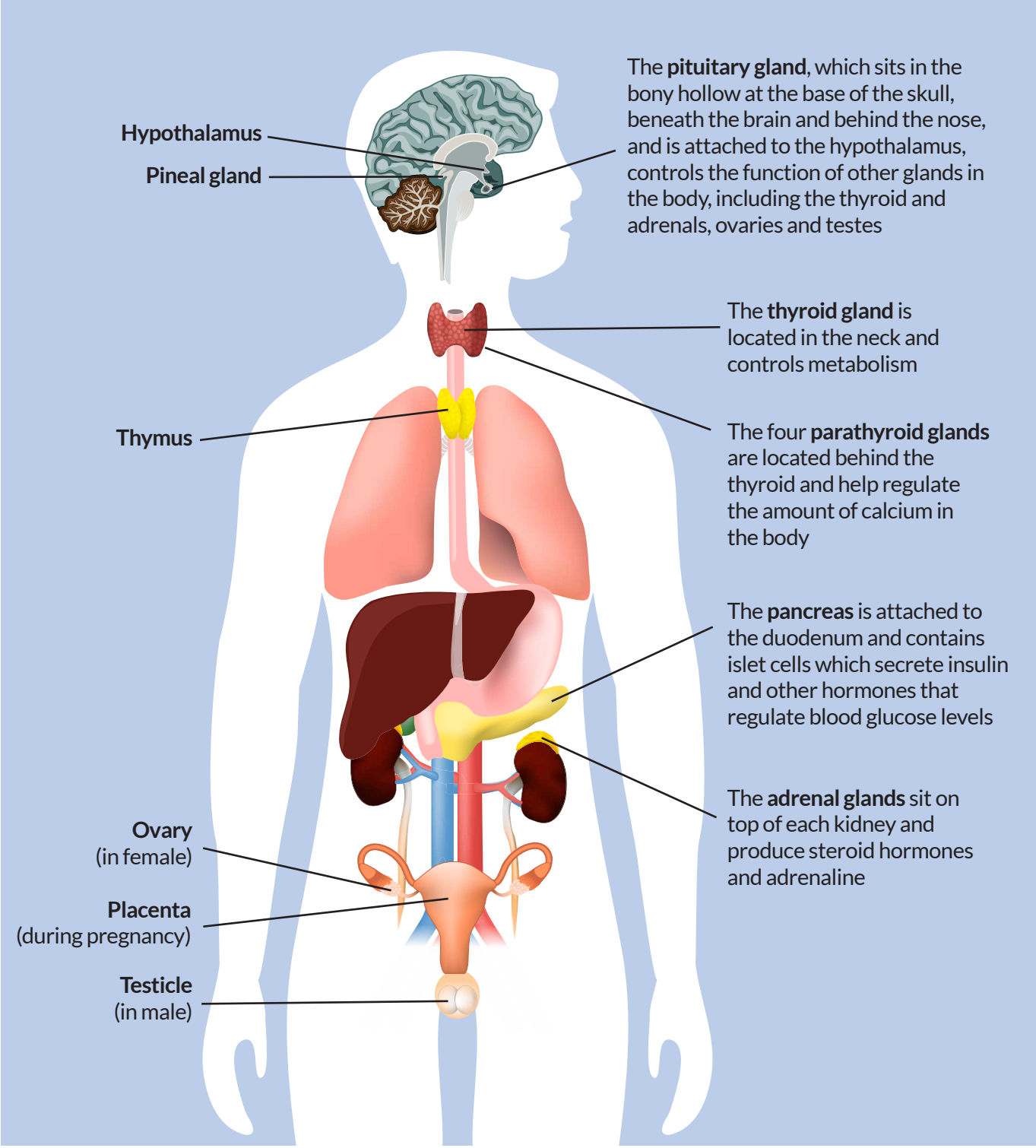
Recommendation	Actions	Owners	Timescale
12. Ensure the endocrinology department is fully optimised to release clinicians' time to care in line with associated NHS People Plan programmes.	**a** To enable better workforce planning and support service delivery, trusts should review the resourcing of their endocrinology MDTs and relevant surgical services considering in particular: i. Employing at least one but ideally two specialist nurses (dependent on department workload/ demand) to carry out pre-investigation assessments for outpatients, lead clinics and support pre/post-operative care. The specialist nurse support for the surgical service may be the same or separate from that for the endocrinology service. Trusts would need to make a business case to ascertain the value of this action. ii. Increasing administrative and clerical resource to provide support for clinics.	Trusts	For immediate discussion
	b GIRFT to work with NHS England and Improvement People Directorate to action specialist nursing workforce needs in endocrinology and encourage uptake of Society for Endocrinology training courses for specialist nurses.	GIRFT, NHS England, NHS Improvement People Directorate	12 months
13. Improve access to weight assessment and management services for patients with complex obesity.	**a** Endocrinology units should appoint a dedicated obesity lead in their team (where they have not already).	Trusts	6 months
	b Trusts should work with integrated care systems to implement Tier 3 obesity services, with a specialist multidisciplinary team in place to assess and manage patients (where they have not already).	Trusts, ICSs	1 – 2 years
	These actions are also endorsed by the GIRFT clinical leads for diabetes.		
14. Accurately assign main specialty and treatment function codes to ensure endocrinology activity is appropriately captured.	**a** Trusts to ensure all endocrinology activity is coded using treatment function code 302, and either main specialty code 300 (general medicine) or 302 (endocrinology), according to the job plan of the consultant who undertook the activity.	Trusts	12 months
15. Ensure there is clear and consistent delineation between outpatient and day case endocrine activity and that pricing arrangements reflect this.	**a** Society for Endocrinology, in collaboration with GIRFT, to produce clear guidelines around which endocrinology procedures should be conducted as day cases (using proposed list - see page 70).	Society for Endocrinology, GIRFT	6 months
	b GIRFT endocrinology team to feed into the GIRFT coding workstream with insight on procedures which require more time/resource than a standard outpatient appointment, but less than day case activity.	GIRFT	12 months
	c GIRFT to work with NHS England and NHS Improvement to review pricing arrangements for outpatient and day case procedures to standardise funding and incentivise best practice.	GIRFT, NHS England, NHS Improvement	12 months

Recommendation	Actions	Owners	Timescale
16. Enable improved procurement of devices and consumables through cost and pricing transparency, aggregation and consolidation, and by sharing best practice.	**a** Use sources of procurement data, such as the NHS Spend Comparison Service and relevant clinical data, to identify optimum value for money procurement choices, considering both outcomes and cost/price.	GIRFT	For continual action throughout the GIRFT programme.
	b Identify opportunities for improved value for money, including the development of benchmarks and specifications. Locate sources of best practice and procurement excellence, identifying factors that lead to the most favourable procurement outcomes.	GIRFT	For continual action throughout the GIRFT programme.
	c Use Category Towers (CTs) to benchmark and evaluate products and seek to rationalise and aggregate demand with other trusts to secure lower prices and supply chain costs.	GIRFT	Upon completion of 1B.
17. Reduce litigation costs by application of the GIRFT Programme's five-point plan.	**a** Clinicians and trust management to assess their benchmarked position compared to the national average when reviewing the estimated litigation cost per unit of activity.	Trusts	For immediate action
	b Clinicians and trust management to regularly discuss with the legal department or claims handler the claims submitted to NHS Resolution included in the data set to confirm correct coding to that department. Inform NHS resolution of any claims that are not coded correctly to the appropriate specialty via CNST.Helpline@resolution.nhs.uk	Trusts	Upon completion of 17A
	c Once claims have been verified, clinicians and trust management to further review claims in detail, including expert witness statements, panel firm reports and counsel advice as well as medical records to determine where patient care or documentation could be improved. If the legal department or claims manager needs additional assistance with this, each trust's panel firm should be able to provide support.	Trusts	Upon completion of 17B
	d Claims should be triangulated with learning themes from complaints, inquests and serious incidents (SIs)/Patient Safety Incidents (PSIs) and, where a claim has not already been reviewed as SI/PSI, we recommend that this is carried out to ensure no opportunity for learning is missed. The findings from this learning should be shared with all front-line clerical staff in a structured format at departmental/ directorate meetings (including multidisciplinary team meetings where appropriate).	Trusts	Upon completion of 17C
	e Where trusts are outside the top quartile of trusts for litigation costs per activity, GIRFT will be asking national clinical leads and regional teams to follow up and support trusts in the steps taken to learn from claims. Clinical leads and regional team directors will also be able to share examples of good practice with trusts.	Trusts	For continual action throughout GIRFT programme

What is endocrinology?

Endocrinology is a branch of medicine that relates to the human endocrine system. The human endocrine system comprises several glands in the body which secrete hormones directly into the blood. These hormones control many complex human functions such as sexual development, reproduction, metabolism, growth and weight gain, to name but a few.

Endocrinology is concerned with the functioning of the glands outlined below.



Disorders of the human endocrine system are hugely varied and wide-ranging and, left untreated, can be life-threatening. They include conditions that require urgent treatment and may necessitate emergency admission, such as phaeochromocytoma, pituitary apoplexy and hypoglycaemia caused by insulinoma, as well as others that are true electives, such as hyperparathyroidism, where treatment can be planned in advance. There are also many endocrine conditions that are relatively easily managed on an outpatient basis.

Endocrinology is a small but very important specialty, which is continuing to evolve rapidly. It is fair to say that endocrine activity is not fully recognised by many trusts. GIRFT deep-dive visits have shown there are a number of trusts that record no endocrinology activity at all. This reflects an ongoing problem with specialty attribution and data collection – a challenge that will be covered in this report. The specialty is growing in importance (the number of outpatient appointments has increased by 31% in the last five years) and it is hoped that the GIRFT process will increase the recognition of endocrinology throughout England and the NHS.

A number of surgical specialties are involved in providing endocrine surgery. In many trusts these surgical services are not well organised and operate on small numbers of patients with uncertain outcomes. We have made recommendations to address this.

As endocrine disorders can include thyroid disease, diabetes and obesity, there is significant cross-talk between specialists. There is also some overlap, which we have noted where it occurs, between endocrinology and other GIRFT reports, including ear, nose and throat (ENT) and diabetes.

Table 1: Examples of a range of endocrine disorders and their treatment

Organ	Condition	Recommended treatment/urgency
Thyroid and parathyroid	■ Hypothyroidism	■ Medication (thyroxine)/urgency varies according to severity
	■ Thyrotoxicosis	■ Medication, radioactive iodine or surgery/ urgency varies according to severity
	■ Hyperparathyroidism	■ Parathyroidectomy/urgency varies according to severity
Adrenal	■ Cushing's disease	■ Surgery/urgency varies according to severity
	■ Addison's disease	■ Steroids/urgent
Pituitary	■ Tumours producing prolactin (prolactinoma)	■ Surgery in all cases (except prolactinoma)/ the urgency of surgery should be determined early by the pituitary MDT
	■ Non-functioning	
	■ Growth hormone overproduction (acromegaly)	
	■ Adenoma producing ACTH (overproduction of cortisol, Cushing's disease)	
Pancreas	■ Diabetes	■ Diet and/or insulin/urgency varies according to severity
	■ Neuroendocrine tumours	■ Surgery/urgent

The relationship between endocrinology and endocrine surgery

For patients with endocrine disorders such as thyroid cancer, surgery is sometimes the best or only available treatment that offers a cure. For other conditions, such as thyrotoxicosis (where too much thyroid hormone is circulating in the body), the patient can choose surgery, treatment with radioactive iodine or continued medical management.

Endocrine surgical procedures are carried out on the thyroid and parathyroid, the adrenal and pituitary glands and the pancreas, or to remove tumours elsewhere (paraganglioma for example, which are tumours that in some cases produce adrenaline and can occur in the head, neck, chest or abdomen) that cause hormonal dysfunction.

The overlap between endocrinology and other specialisms means that surgeons with a range of clinical backgrounds may perform endocrine procedures, but it should be noted that the general surgery curriculum allows specialist training and examination in endocrine surgery as a distinct sub-specialty. Trainees who have taken this part of the Fellowship of the Royal College of Surgeons (FRCS) exam are often called endocrine surgeons. For an overview of endocrine surgery see Table 2 below.

Surgery for morbid obesity is not covered in this report.

Table 2: Overview of endocrine surgery

Gland	Type of surgery	Surgeons who perform this procedure	Surgical practice and training
Thyroid and parathyroid	Part or complete removal of thyroid/ parathyroid, excision of thyroid or parathyroid tumours	■ Endocrine surgeons ■ ENT surgeons ■ General surgeons	Surgery of the thyroid and parathyroid is covered in the curriculum of surgeons training in ENT and general surgery. Some general surgeons offer thyroid and or parathyroid surgery in addition to another surgical sub-specialty while others devote the whole of their time to endocrine surgery (endocrine surgeons). Some ENT surgeons devote all or most of their time to treating patients with thyroid conditions, while others include thyroid surgery alongside a more general ENT practice or surgery for head and neck cancers.
Adrenal	Partial or complete removal of the adrenal gland, excision of adrenal tumours.	■ Endocrine surgeons ■ Urologists ■ General surgeons	Most endocrine surgeons operate on the adrenal gland. Adrenal surgery is in the general surgery curriculum for the sub-specialty endocrine surgery but not in the curriculum of surgeons training to be urologists. It has become custom and practice that some urologists offer adrenal surgery in some hospitals.
Pituitary	Excision of pituitary tumours	■ Neurosurgeons ■ ENT surgeons (jointly working with neurosurgeons)	Removal of intracranial tumours from within the brain is covered under the specialist neurosurgery curriculum.
Pancreas	Excision of the rare gastrointestinal and pancreatic endocrine tumours. Partial or occasionally complete removal of the pancreas.	■ Endocrine surgeons ■ Other sub-specialties of general surgery, particularly hepatobiliary and pancreatic surgeons.	Some but not all endocrine surgeons operate on rare gastrointestinal and pancreatic endocrine tumours. Pancreatic endocrine surgery is usually performed in centres offering surgery for the more common form of (exocrine) pancreatic cancer.

ENT and general/endocrine surgeons are represented by the British Association of Endocrine and Thyroid Surgeons (BAETS), which supports appropriate standards for endocrine surgery and maintains the United Kingdom Register of Endocrine and Thyroid Surgery (UKRETS). ENT UK, the representative body for ENT surgeons also recommends that thyroid surgery is audited through UKRETS.

It is vital that surgeons work very closely with endocrinologists and anaesthetists in multidisciplinary teams (MDTs) to optimise outcomes for patients who need or choose to have surgery for endocrine disorders. There are currently national recommendations for multidisciplinary team working for thyroid cancer[4] and for adrenal[5] and pituitary surgery,[6] and there is no doubt that in successful units there is strong collaboration between these specialties for all endocrine patients whose management involves surgery.

Current challenges facing endocrinology

In 2018/19 the specialism recorded 626,686 adult outpatient attendances. This number has been growing steadily over the last five years (31% increase as opposed to the 17.5% increase seen in outpatient attendances in general across the NHS).[7]

In England there are currently 125 endocrinology departments.[8] We defined these as centres that see more than 100 patients (new referrals and follow-up appointments) per year, 44 of which are specialist centres.

While we did not explore paediatric endocrinology, defined as services for those under 18 years of age, we believe the variation found in adult services is also occurring in care for younger people. We do not present evidence to support this, but hope that the recommendations of the report will be applied to both adult and paediatric endocrinology services.

The GIRFT process has identified wide variations in data about endocrinology that does not reflect what we know to be true. This is partly due to a historical anomaly regarding 'main specialty' and 'treatment function' code assignment, with the result that endocrinology, as a specialty, is not as visible as it should be in England. Coding is covered in detail in a separate section. (see page 66)

A related issue is that the data does not currently allow a clear distinction between specialist and non-specialist endocrinology. This not only affects optimal commissioning of specialised/non-specialised services but also, potentially, hinders prompt and timely referral of patients to specialist care.

We outline a typical patient pathway below, followed by a description of the main challenges facing the specialty at each stage. (For a more detailed discussion see Optimising patient pathways - page 21).

[4] *National Institute for Clinical Excellence (NICE) (2004), Improving outcomes in head and neck cancers. https://www.nice.org.uk/guidance/csg6*

[5] *Palazzo, F., Dickinson, A., Phillips B. et al., (2016), Adrenal surgery practice guidance for the UK, 2016. www.baets.org.uk/wp-content/uploads/Adrenal-Surgery-Practice-Guidance-for-the-UK-2016.pdf*

[6] *National Institute for Health and Care Excellence (NICE) (2006), Improving outcomes for people with brain and other CNS tumours. https://www.nice.org.uk/guidance/csg10*

[7] *HES data on outpatient attendances 2013/14–2018/19.*

[8] *We visited 126 trusts, two of which have since merged. See Appendix 1 for details.*

Typical patient pathway

Referral

The patient visits their GP with health concerns. Based on their symptoms, the GP may first conduct or commission tests or may refer them directly to an endocrine service for investigation, diagnosis and treatment, if appropriate. Timely referral in accordance with best practice improves the likelihood of a good outcome.

Referral – challenges

Referral from primary care may be delayed or hampered by slow or inappropriate testing or by referral to the wrong level of care (i.e. not referring a patient directly to specialist care where this is indicated).

Access

After the patient has been referred to the endocrinology team they will be assessed via case history and diagnostic tests, usually conducted on an outpatient or day case basis. Pre-clinic testing protocols for different endocrine conditions will improve the efficient running of a clinic by decreasing the number of repeat outpatient clinic visits that are needed. Results should be discussed by an MDT where appropriate. Depending on the outcome, the patient may be discharged if no treatment is required, referred on to a specialist service, referred for surgery, offered a course of treatment or given help and advice to manage their condition themselves. GPs may refer thyroid lumps and goitres directly to a surgical team. Some referrals to endocrinologists are redirected to a surgical team in some centres, where appropriate. Patients with possible thyroid cancer are best referred on the two-week wait cancer pathway to ensure prompt investigation. This should not be delayed by requesting scans before referral.

Access – challenges

Access to endocrine services at the appropriate level, including endocrine surgery, may be delayed because of inefficiencies in booking/conducting tests after initial referral (i.e. duplication of certain tests or multiple tests scheduled on different dates) as well as long waiting lists and/or poor list management/communication. Patients requiring surgery urgently who do not have a suspected cancer may find their surgeries postponed in favour of patients with malignant tumours. Access may also be made more difficult because of remote locations or a lack of co-ordination across sites.

For patients requiring weight management services, access can be particularly problematic because there is a lack of provision across the country, with only 44% of trusts offering obesity services at Tier 3 level or above.

Patients with possible thyroid cancer can have surgery delayed by being seen first in an endocrinology clinic rather than a surgical thyroid clinic if the endocrinology team are not familiar with the correct pathway.

Not all endocrinologists refer all patients who may benefit from parathyroidectomy for a surgical consultation. NICE guideline 132 covers recommendations for referrals for surgery for parathyroidectomy.

Surgery

Where surgery is indicated,[9] the endocrinologist will refer the patient to a suitable and experienced surgeon or MDT. When considering a surgeon we recommend consulting UKRETS and/or BAETS to check that the surgeon undertakes suitable numbers of the procedure in question and has acceptable outcomes.

This should be a shared decision based on information the referring clinician has discussed with the patient. It is important not to make assumptions about the information patients might want, the clinical or other factors a patient might consider significant or a patient's level of knowledge/understanding of what is proposed.[10] Patients with goitre and thyroid lumps may be referred directly to a surgeon, especially when investigations for cancer are required. These investigations are best done through a thyroid lump 'one-stop' clinic with access to ultrasound imaging and fine-needle or core biopsy.

Surgery and post-operative care will ideally be managed within an MDT that employs at least one specialist nurse with endocrinology training. Patients with cancer should have access to a suitably trained cancer nurse specialist.

Patients with complications related to endocrine conditions may require separate referrals. For example, patients with significant thyroid eye disease should be referred to an ophthalmic surgeon who also usually works in an MDT for ophthalmic Graves' disease.

Surgery – challenges

Access to a surgical team (where required) with the correct level of expertise and support may be compromised by a lack of robust audit data on outcomes (affecting both commissioning patterns and the patient and referring endocrinologist's ability to make an informed choice) and, related to this, by the existence of surgeons/trusts that perform procedures at low volumes. This can have an impact on outcomes, length of stay and complication rates, because teams may lack experience and therefore expertise in particular conditions/procedures.

Surgeons who do not participate in audit will be unable to convey the risks of surgery in their hands to endocrinologists and patients. For referrals to surgeons directly from GPs there must be a robust pathway to ensure patients are seen by a surgeon with appropriate expertise.

Support and follow-up

For patients who have had endocrine surgery and those facing life-changing conditions or ongoing treatment, support and follow-up are important. This includes patients who need to be monitored for post-surgical complications over time, who have a condition that requires ongoing monitoring and/or self-care and where treatment and management involve long-term observation and/or repeated procedures. Access to clinical nurse specialists for patients with thyroid and other endocrine cancers is beneficial but not widely available. It is important that patients understand what to expect in the way of follow-up care and that this is made clear at the point of discharge. It is also helpful to signpost patient organisations, if this has not already been done.

Support and follow-up – challenges

Support and follow-up may be compromised where there are no endocrine specialist nurses within the team and where clinics are not located in convenient locations or available remotely through electronic means. Poor administration can also affect a service's ability to provide support for patients. If patient support and follow-up is not well managed, or is devolved back to primary care without adequate planning, there may be gaps in provision.

[9] *National Institute for Health and Care Excellence (2019), Hyperparathyroidism (primary): diagnosis, assessment and initial management (NG132), https://www.nice.org.uk/guidance/ng132*

[10] *General Medical Council (GMC) (2008), Consent: Patients and doctors making decisions together, www.gmc-uk.org/-/media/documents/gmc-guidance-for-doctors---consent---english_pdf-48903482.pdf?la=en&hash=588792FBA39749E57D881FD2E33A851918F4CE7*

About our analysis

We carried out our analysis following the established GIRFT model (see page 79).

Identifying endocrinology service providers

First we set about assembling all of the relevant existing NHS data on endocrinology. However, identifying the hospitals that provide endocrinology services proved surprisingly difficult due to issues of incorrect specialty coding. We cover this in detail under Improving data quality and data collection (see page 66). Eventually we were able to identify 126 trusts with some activity in endocrinology.[11]

Collecting additional data

We conducted our own supplementary data collection through an extensive questionnaire to providers (Appendix 4 - page 90). Where the data allowed, we benchmarked providers on key measures and identified where there was variation. We received responses from 109 trusts.

Carrying out deep-dive visits

Deep-dive visits with providers are a vital part of the GIRFT process. At these meetings, we reviewed data at trust level, engaging with clinical and managerial staff to review performance, provide advice and gather views and opinions.

We provided every trust with a data pack. We then visited 126 trusts to discuss the data in depth. During these deep-dive visits, we looked closely at the national variation in clinical data. We discussed this detail at length with physicians and surgeons, senior provider management and all those involved in delivering endocrinology services.

We also discussed our findings with the Society for Endocrinology and BAETS.

Overlap with other specialties

Thyroid surgery was covered in part in the GIRFT ENT report. The endocrinology report builds on this and adds depth as well as capturing thyroid surgery performed by endocrine and other surgeons with a general surgical training.

In recent years the number of thyroid operations has steadily increased. This has been driven, at least in part, by the detection on neck ultrasound of asymptomatic nodules of indeterminate nature. These are referred for investigation, and for many patients a definitive diagnosis can only be established after surgery. During this time the number of operations performed by endocrine/general surgeons has remained fairly static, though distributed amongst fewer surgeons as specialisation in endocrine surgery developed. Thyroid surgery is increasingly performed by ENT surgeons, who now perform more than half the total number of operations per year. Overall, the mean number of thyroid procedures per individual surgeon has fallen recently from 12.5 to 11.6 between 2013/14 and 2017/18.[12] The mean number of cases per trust also fell from 26.3 to 24.5. This suggests that national guidelines (recommending a minimum of 20 cases per surgeon) are not being followed consistently.

There is also a significant overlap with diabetes (obesity) and, to a lesser extent, with rheumatology e.g., osteoporosis.

[11] *Two of these trusts have since merged. A full list of trusts visited can be found in Appendix 1*

[12] *Gray, W. K. (Senior Research Associate GIRFT Programme), Analysis of HES data.*

Optimising patient pathways

Capacity problems and significant delays in outpatients were identified in 66% of trusts visited. Clear and appropriate patient pathways are vital to ensure that patients receive a timely referral, diagnosis and treatment in line with best practice. It is particularly important that the pathway leads directly to referral to a specialist centre where appropriate. There are in fact clear referral pathways for the most common endocrine conditions, but they are not consistently applied, which indicates a need for a standardised approach. For serious endocrine conditions, a delayed referral can be fatal.

Where surgery is indicated, the pathway should be well defined at every stage, i.e. through pre-assessment, surgery, post-operative care, discharge and follow-up. Endocrinologists should refer to surgeons who can demonstrate through audit that they operate on an adequate number of patients and achieve good outcomes. This is particularly important where surgery is for rarer/more complex conditions. We outline what constitutes an adequate number for various types of surgery in the section on Concentrating key procedures (see page 39).

In all cases where surgery or treatment is advised, it is important that the decision making around this is patient-centred, and that the patient has been given information (in verbal and written form) about their diagnosis and treatment options. Patients should not be required to consent to treatments without the opportunity to consider the patient information and to ask follow-up questions, nor should they be expected to interpret audit data on surgeon experience, for example, without help and guidance from their GP or referring clinician. Patients should also be given a point of contact to raise questions between appointments – ideally a specialist nurse*.

> *We regularly hear from patients who feel they are being hurried towards surgery or RAI but have significant unanswered questions and they have no contact with the hospital team who would be able to answer them.*
>
> **The British Thyroid Foundation**

Ideal patient pathway: Adrenalectomy for phaeochromocytoma

Phaeochromocytoma should only be managed by a specialist MDT. This is potentially complicated surgery requiring an experienced surgeon and an equally experienced anaesthetist. The possibility of multiple endocrine neoplasia (MEN) and associated tumours must be considered. Specialist imaging is required.

Once diagnosis is established, the endocrinologist will begin appropriate medical management and work with the surgical and anaesthetic team to agree a date for surgery. The urgency will depend to some degree on presentation and response to medical management. Once the patient is fit for surgery there is no advantage to delay, but it is crucial to ensure the right team and environment for surgery and postoperative recovery is in place.

Because of the complexity of preparation and the need to ensure all team members are available for surgery, every care must be taken to avoid cancellation for non-clinical reasons.

Most patients can be discharged within 1-2 days of laparoscopic surgery or 3-4 days for open surgery. Post-operative medication on discharge should be agreed with the endocrinologist. Some tumours co-secrete cortisol, creating a risk of Addison's syndrome postoperatively

Follow-up at two weeks to discuss histology and recovery should be routine. In the absence of any ongoing problem with surgical recovery, such as a wound infection, the patient's further follow-up and monitoring is best done in an endocrinology clinic.

*Throughout this report when we use the term nurse we are referring to a registered nurse.

Ideal patient pathway: Hyperparathyroidism

(follow NICE guideline NG132, May 2019)

Patient referred from GP, endocrinology or other specialty, e.g. urology.

First surgical appointment should align with and allow for the 18-week elective pathway from referral to treatment.

The physician and/or surgeon should satisfy themselves that diagnosis has been correctly established. Following this the surgeon should provide the patient with information on the pros and cons of the surgery. This ensures that any consent to surgery is informed and supported.

In order to relieve symptoms and stop/reverse the metabolic consequences of hyperparathyroidism surgery should be timely. An assessment of clinical priority must be made. For patients with mild symptoms and stable calcium levels, in the absence of specific national guidelines we suggest a target for surgery within 12 weeks of making the decision (with the proviso that this should fall within the 18-week patient pathway). If there are delays to surgery the patient may need regular checks to ensure no deterioration in their condition. At the other end of the spectrum, patients may need to be admitted under the care of an endocrinologist for urgent management of complex and/or severe hypercalcaemia at a specialist centre and urgent surgery planned if conservative measures such as rehydration and cinacalcet do not bring the calcium down to an acceptable level. Urgent surgery may also be considered for hypercalcaemia in pregnancy.

The majority of elective patients are suitable for day case or overnight surgery.

The risk of hypocalcaemia can be predicted to a large extent from the surgical findings and number of parathyroids removed. Discharge advice can be based on post-operative albumin-adjusted serum calcium and PTH levels a few hours after surgery. Some centres discharge on a prophylactic dose of supplemental calcium, but there is no consensus on this. Selected patients can be brought back for further blood tests rather than staying in overnight.

Patients should have an opportunity to discuss the outcome of surgery ideally within two weeks and no more than four weeks after surgery, when the pathology report is available. Albumin-adjusted serum calcium may be re-checked at this time and again at three to six months to confirm whether the surgery has been successful. If calcium is above the normal range the results should be discussed with the surgeon and endocrinologist, as this suggests the patient has not been cured or has relapsed. This is the case for less than 5% of patients. Where the condition is not cured by the first operation the patient should be referred to a specialist centre. Assuming surgery has been successful, calcium is re-checked yearly after this by the GP. No further routine surgical follow-up is required, but further endocrinology appointments may be needed to manage osteoporosis and renal stones (see also appendix 5 on page 97).

Ideal patient pathway: Cushing's syndrome - urgent referral (pituitary or adrenal surgery required)

Patient referred from GP to endocrinology.

Investigation within secondary care should be completed within two weeks and wherever possible within a one-stop clinic. All investigations should be reviewed by a specialist endocrinologist at an MDT meeting within two further weeks to facilitate prompt decision-making. As soon as Cushing's is suspected the endocrine MDT should be contacted.

Where further investigations are required, they should again be completed in a one-stop setting, ideally on the endocrine day unit, supported by one whole-time equivalent pituitary nurse. Inferior petrosal sinus sampling (a Cushing's-specific investigation that is extremely technically difficult to perform) should be available regionally and conducted as a defined requirement by a suitably skilled MDT familiar with the procedure.

Investigations at the specialist centre to reach a diagnostic conclusion should be completed and results discussed within one month, followed by referral for definitive treatment within two weeks.

Cushing's syndrome requires pituitary surgery if Cushing's disease is the underlying cause or adrenal surgery where an adrenal tumour is present. Surgery should be conducted by a centre with familiarity with the condition by a surgeon who operates on an appropriate number of such cases and records outcomes.

There is a strong statistical correlation between volume and length of stay for pituitary surgery in England. Short stay pathways should be aimed for, certainly with 1–2 days being realistic.

Long-term follow-up to establish cure, post-operative pituitary function and later recording of adrenal function and/or pituitary tumour recurrence is normally available at the pituitary specialist centre or by arrangement at a local centre with experience in follow-up of these patients.

Referral and investigation

Duplicative or poorly scheduled testing can delay referrals, cause bottlenecks for patients and wastage within the system. In pituitary and adrenal referrals in particular, we have heard that tests can be needlessly repeated. From our questionnaire and deep-dive visits it was apparent that there is some variation – and some overlap – in the tests commissioned by GPs pre-referral and those conducted after referral to the endocrinology teams. Clearer visibility in both directions on the electronic patient record/improved referral letter format would support greater clarity around tests conducted/requested, as well as any follow-up after diagnosis and treatment. In order to avoid bottlenecks for such patients, pituitary or adrenal testing arrangements, perioperative care and follow-up arrangements should be clearly delineated between the referring and referral centres. Where tests are commissioned in primary care these should be of the same standard as would be expected in secondary care (e.g. thyroid ultrasounds should be reported to standards set out in NICE guideline 145)[13] and the results should be available for review by the secondary or tertiary care teams.

> *Once a diagnosis has been reached patients should be signposted to the resources and information offered by the many reliable patient organisations for endocrine disorders.*
>
> **The British Thyroid Foundation**

[13] *National Institute for Health and Care Excellence (NICE) (2019), Thyroid disease: Assessment and management (NG145), https://www.nice.org.uk/guidance/ng145*

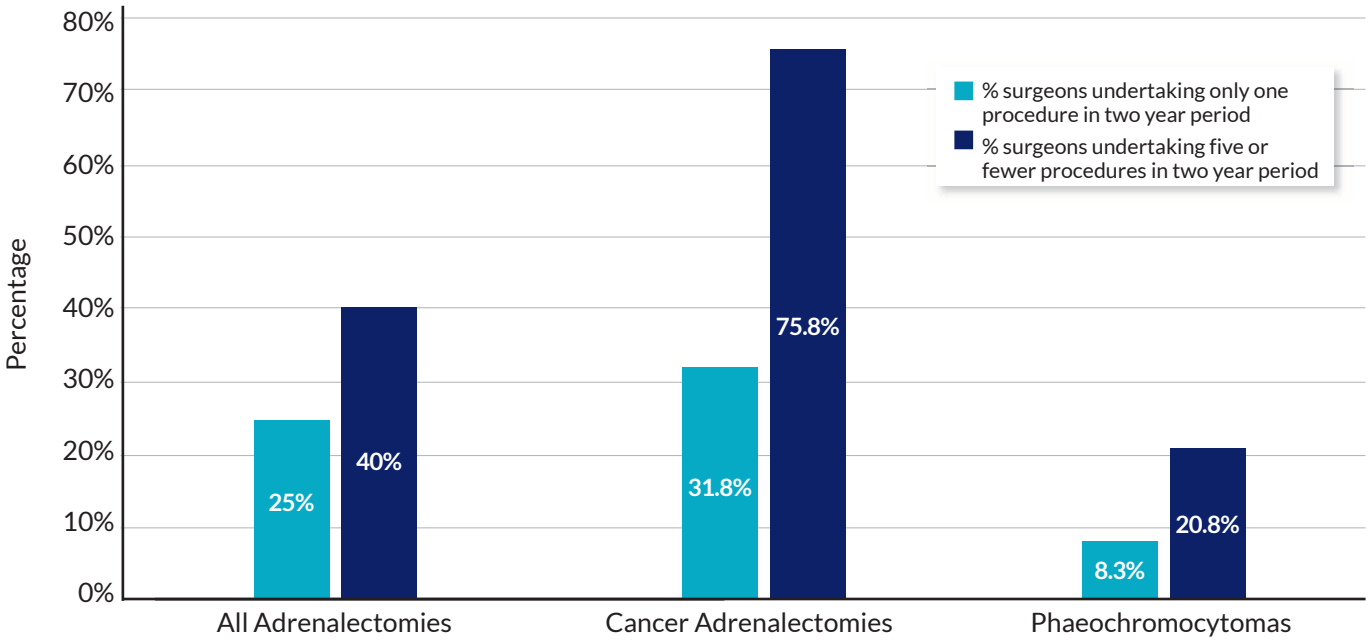
There is at present a lack of clear guidance around thresholds for referral to specialist care. This reflects a historic situation whereby trusts have assessed themselves against the criteria for specialist endocrine services. Due in part to the cross-cutting nature of endocrinology, individual trusts' self-assessments have been variable in their accuracy, so a trust that meets the criteria for delivering specialised thyroid services, for example, may not be suitably equipped or staffed to deal in the most appropriate way with other complex endocrine conditions, and this may not be clear at the point of referral. There is currently a new specification for specialised endocrine services in development,[14] which seeks to clarify this by setting clearer criteria for specialised services by subspecialty. This means that trusts can clearly indicate their ability to provide specific specialised services. It is not expected that all trusts will offer all services. We fully support this work (see Recommendation 2).

A number of conditions and procedures are subject to specific commissioning guidance and policies, either at a national or local level. Where national guidance exists – such as that developed by the Evidence-Based Interventions Programme or NICE[15] – it should be followed.

There is also no universal way to flag patient notes for specialist/non-specialist care. When a patient requiring specialist care (i.e. for a pituitary tumour[16] or suspected Cushing's syndrome, which is indicated by the presence of an adrenal adenoma over 4cm in size) is not referred to the appropriate centre this causes unwarranted delays in diagnosis and treatment and may affect outcomes.

Related to this, there is a particular need for adrenalectomies (a complex procedure involving some significant risk of poor outcomes) to be undertaken only by surgeons who are sufficiently experienced in these procedures and undertake an appropriate number.[17] Where this is not the case, we have recommended that the surgeons concerned no longer perform this procedure and that they amalgamate with a specialist centre to which they can refer adrenalectomies. Our deep-dive visits revealed 48 surgeons from 23 trusts carrying out adrenalectomies at volumes that are clinically inappropriate (under six non-cancer adrenalectomies per surgeon per year or under 20 if they are operating on patients with adrenal cancer and phaeochromocytoma). See Figure 1 below. These centres should no longer offer these procedures but instead refer patients to surgeons with more regular practice. The alternative is for two or more centres in close proximity to work as one unit until surgeons perform adequate numbers per year. It may be beneficial for two consultants to work alongside each other (dual operating) to develop and maintain adequate experience. Figure 1 below gives an overview of low-volume adrenal procedures. Low-volume procedures are covered in more detail in the section on Concentrating key procedures (see page 39).

Figure 1: Overview of low-volume adrenal surgery



Data reported from GIRFT Endocrinology Supplementary Questionnaire, with responses from 109 Trusts / Sites. Data for 2 year period from 1/4/16 to 31/3/18.

[14] *NHS England Endocrinology Clinical Reference Group, Service specification for specialised endocrinology (adult), in development 2020.*

[15] *For example, National Institute for Health and Care Excellence (NICE) (2019), Hyperparathyroidism (primary): Diagnosis, assessment and initial management (NG132), https://www.nice.org.uk/guidance/ng132/chapter/Recommendations#referral-for-surgery*

[16] *National Institute for Health and Care Excellence (2006), Improving outcomes for people with brain and other central nervous system tumours (CSG10), https://www.nice.org.uk/guidance/csg10*

[17] *Newell-Price, J., Wass, J., Wiebke, A. and Palazzo, F. (2016), Adrenal surgery – time for change, Endocrinologist 120, Summer 2016. www.endocrinology.org/endocrinologist/120-summer16/features/adrenal-surgery-time-for-change/*

Access – from outpatient visit to treatment/surgery to discharge

We heard on our deep-dive visits that NICE guidelines for suspected cancer recognition and referral[18] are having some unintended consequences for the referral and treatment of equally serious/urgent but benign conditions. For example, small thyroid cancers with no expected impact on life expectancy are fast-tracked, but patients with severe and potentially life-threatening conditions due to over-activity in endocrine organs (such as, for example, multi-nodular goitre with airway compression and severe hyperparathyroidism) can remain on waiting lists for up to 11 months in some trusts, when other referrals are prioritised. Bearing in mind the current 18-week referral to treatment guidance, trusts should make every effort to give such cases clinical priority for new appointments and avoid long delays to surgery.

Networks in endocrinology care

The aim of network working is not to concentrate all resources in a single location, but to encourage trusts to work together to balance workload, provide timely and appropriate care (especially emergency care) and ensure patients are treated by teams with greater experience in their condition. This way of working will also benefit patients in need of obesity services, ensuring access within a network to Tier 3 and Tier 4 services.

We have seen in other specialties, as well as endocrinology, the positive impact a network can have in providing timely and equitable care. By studying existing methods of working, we can better understand the framework on how networks can be developed. We understand what key elements make them successful. These include:

- an enthusiastic lead who engages and has respect of colleagues in the proposed network;
- administrative support to enable cross-site meetings;
- data sharing agreements across trusts that are actively managed;
- technical support that can flexibly span the entire network.

Perhaps the most crucial is an understanding that it is not just about centralising services but rather being flexible to adapt services where there is a need. This may include a trust giving up some routine work in order to focus on more complex or rare cases. To do this, specialised centres need to be identified within an agreed geographical area.

In order to reduce variation and ensure consistent provision of care and in turn outcomes, trusts should collaborate to produce agreed local guidance and protocols for managing conditions. By providing care in line with agreed local guidance trusts can ensure that care is equitable as well as effective. Cross-site working, such as MDTs, can be streamlined by adhering to set criteria when addressing each patient case.

There is no 'one size fits all' solution for integrated and collaborative working. We encourage trusts to continue working with relevant stakeholders (nearby trusts, primary care, commissioners, STPs, Integrated Care Systems and others) to identify core criteria for a network model in every specialty, not just endocrinology. The GIRFT team will work with NHS England and professional endocrinology bodies to help define key requirements and ensure the recommendations of this report are included as criteria when reviewing new ways of working. It is our hope that by doing this, patients will benefit from this model, with appointment options that are more accessible and access to experienced teams when it is needed most.

Trusts will no doubt benefit through reduced variation and improved patient flow, allowing treatment targets to be achieved within the designated timeframes. It is important to ensure new services will be sustainable with respect to quality, best practice and of course, financially. The NHS has resources available to support the development of networks.19

We recommend appropriate audit in order to ensure such changes are having the desired effect and to allow changes in working practice if the need arises.

Day case procedures

There is a lack of clarity around what constitutes a day case procedure for medical endocrine services. This highlights a need for clearer guidance on which procedures should be booked as day cases and which as outpatients. This issue is also linked to data capture and this is covered in more detail in the section on Improving data quality and data collection (see page 66).

[18] *National Institute for Health and Care Excellence (2015, updated 2017) Suspected cancer: Recognition and referral (NG12), https://www.nice.org.uk/guidance/ng12/*
[19] *https://www.networks.nhs.uk/*

Day case surgery

While there is a general move towards increasing the proportion of day case surgery across the NHS, this always requires careful clinical assessment and informed consent from patients through a process of shared decision-making.

In 2021 BAETS released a position statement following the review of the safety of day case thyroid surgery.[20] Its review indicates that, while patients at high risk of bleeding can be identified, it is not possible to identify with any confidence a group of patients with a very low risk. Even when post-operative haemorrhage happens in the relative safety of a surgical ward, the outcome can be catastrophic.

BAETS recommends therefore that day case surgery should be restricted to low-risk hemithyroidectomy cases only. Wards accepting thyroid patients should have detailed information on how to manage post-operative complications available to all staff, both surgical and nursing. Further, the protocol for post-thyroid bleeds should be prominently displayed in the ward. Patients must be provided with a clear action plan in the event they experience swelling/dyspnoea following discharge. If a unit offers hemithyroidectomy as a day case, the unit must provide the patient and their carers the same detailed information as part of shared decision-making, taking into account patient preferences, availability of transport, local geography and family support. Informed consent must include all risks, including the small additional risk of an off-site postoperative bleed and its consequences.

The GIRFT Ear Nose and Throat (ENT) workstream found a number of units undertaking day case thyroid surgery, with 16 units reporting day case rates of above 10%. These units all reported that they are comfortable carrying out benign thyroid surgery as a day case and have not had any problems. We believe it is essential that all such surgery is recorded in the UKRETS national database so that sufficient numbers accumulate nationally and the actual risk of poor outcomes, including death, can be ascertained with a high degree of certainty.

Length of stay

Our deep-dive visits and questionnaire data highlighted significant variations in length of stay after surgery and lengths of stay that were generally longer than we would recommend. Targets for discharge are useful. We would recommend, for example, the following targets, but accept that a small proportion of patients may need longer stays:

- parathyroidectomy for primary hyperparathyroidism: 90% day case;
- thyroid lobectomy: 90% one night (some units offer this as a day case);
- total thyroidectomy for goitre, Graves' disease or cancer without lateral neck dissection: 90% no longer than two nights.

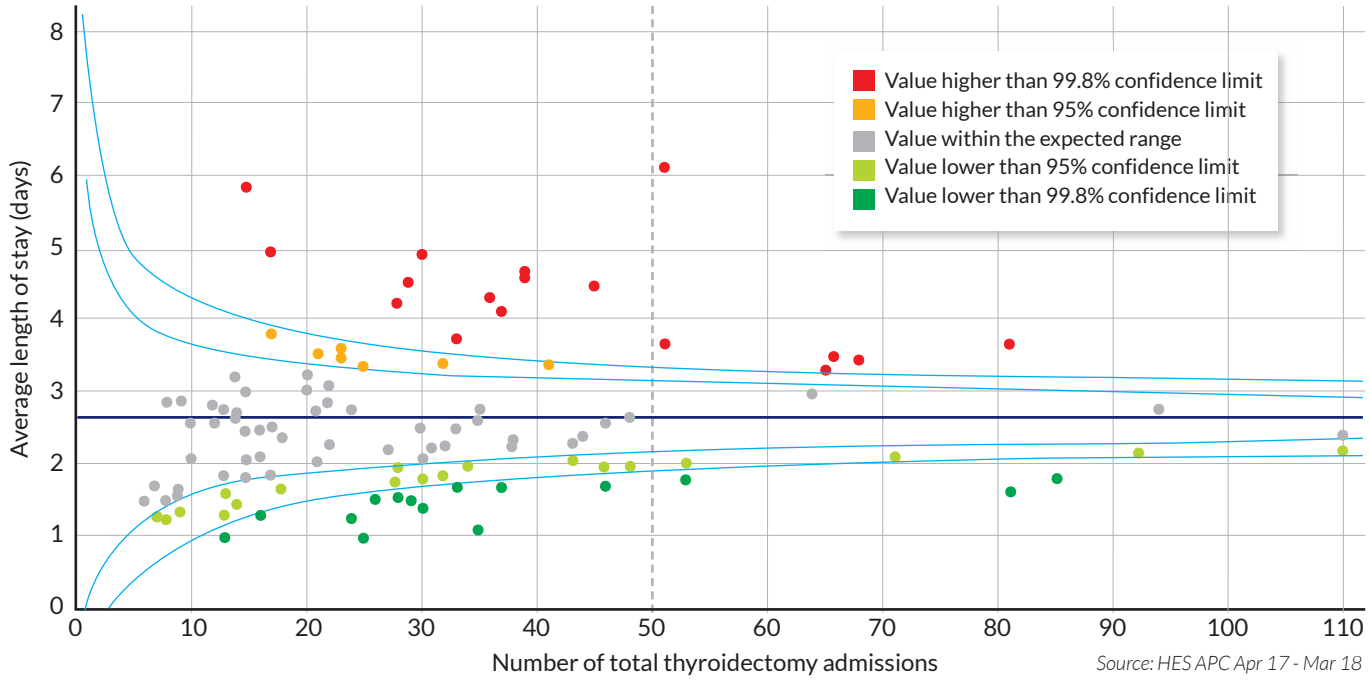
With clearer targets in place, pathways can be streamlined to reflect patient need, by procedure. Longer than average stays may also indicate the need for hub-and-spoke/centralised models for specialised surgical procedures with MDT working and also for at least one, preferably two, nurse specialists with endocrinology training per service to further streamline care pathways. This is covered in greater detail in the sections on 'Concentrating key procedures' (see page 39) and 'Workforce' (see page 55). Figures 2, 3, 4 and 5 below highlight the unwarranted variation we found in lengths of stay for a range of endocrine procedures.

Figure 2 highlights unwarranted variation in length of stay for patients after total thyroidectomy. It shows wide variation, with a significant number of providers having average lengths of stay above the 99.8% confidence limit. There is a five-day difference between the providers with the lowest length of stay and those with the highest.

The financial implications are significant. Every additional bed day incurs an estimated cost of £339 to the NHS. In addition, the average length of stay is too high – a fairly large number of providers are achieving lengths of stay of less than two days, which all should aspire to.

[20] *https://www.baets.org.uk/wp-content/uploads/BAETS-position-statement-on-day-case-hemi-thyroidectomy.pdf*

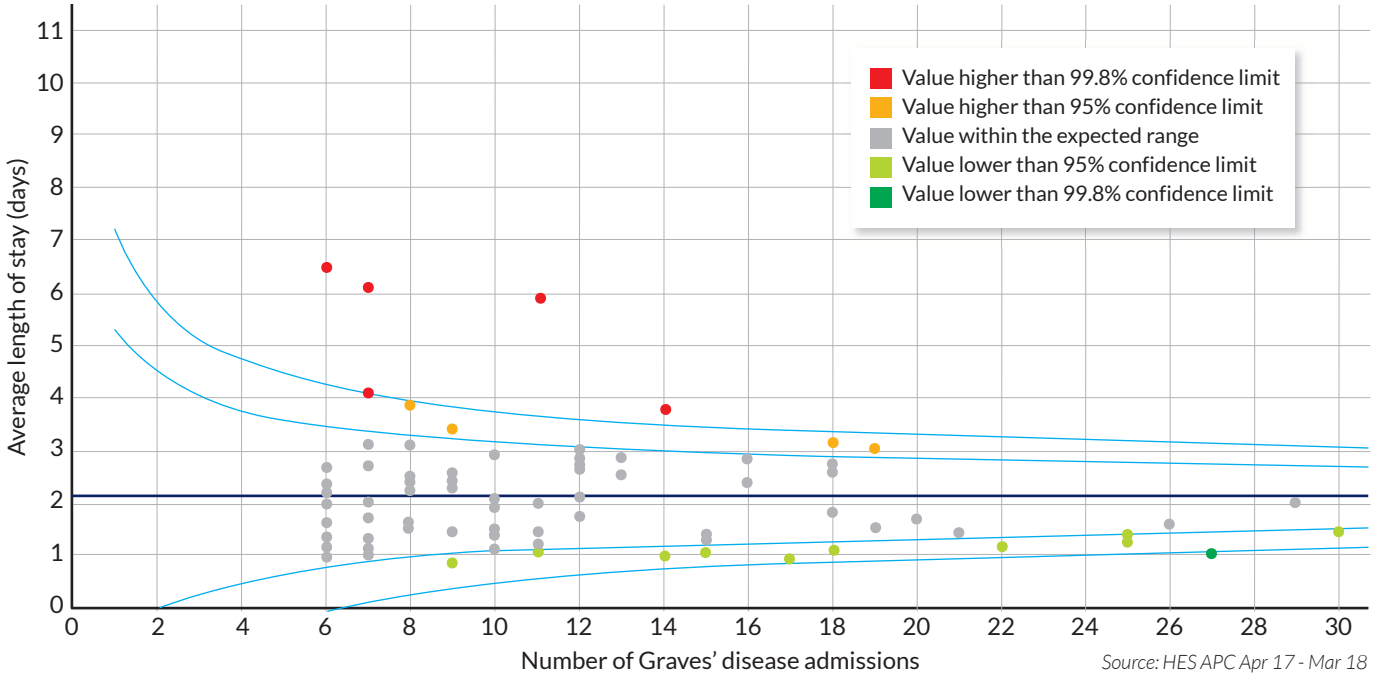
Figure 2: Average length of stay for total thyroidectomy patients (each point on the graph represents one trust)



Source: HES APC Apr 17 - Mar 18

Figure 3 below shows unwarranted variation in length of stay for patients after surgery for Graves' disease. Total thyroidectomy for Graves' is associated with a similar risk of hypoparathyroidism (when damage to the parathyroids causes hypocalcaemia) as surgery for thyroid cancer. Low serum calcium can lead to delayed discharge. The rate of temporary and, more significantly, permanent hypoparathyroidism is a measure of surgical proficiency in preserving the parathyroids. Other complications that can delay discharge include post-operative haemorrhage and injury to the recurrent laryngeal nerve.

Figure 3: Average length of stay for surgical Graves' disease patients



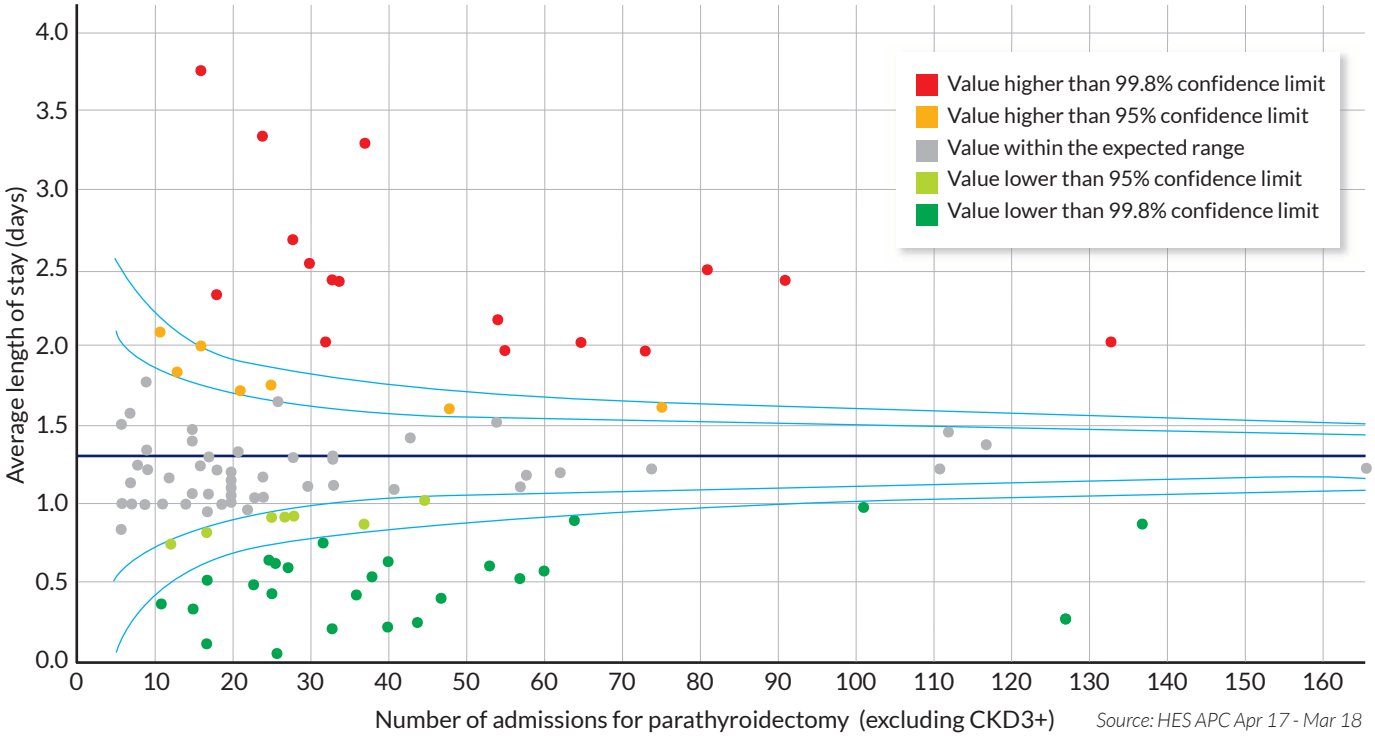
Source: HES APC Apr 17 - Mar 18

The numbers are much smaller for this type of surgery, but we still see outliers above the 99.8% confidence limit and unacceptably wide variation in length of stay (approximately six days). There is some indication that higher-volume providers have lower lengths of stay (covered under Concentrating key procedures - see page 39). Patients in units that cared for 20 or more such patients a year had average lengths of stay of under two days. This is likely to reflect surgical proficiency and a good understanding within the team of the pathway and processes for early discharge.

It may be more difficult to ensure such a high-quality service with low patient volumes since staff will be less familiar with perioperative care, e.g. managing hypocalcaemia,[21] for this condition. Overall, the average length of stay is higher than we would hope, which inevitably has a negative impact on service provision and, by implication, on patient outcomes.

Figure 4 below examines variation in average length of stay for patients with primary hyperparathyroidism. The funnel plot shows significant variation, with a large number of outliers. This is suggestive of significant unwarranted variation and it seems likely that the current average across all providers is too high, particularly given the number of outliers both above and below the outer confidence limits.

Figure 4: Average length of stay for primary hyperparathyroidism admissions (excluding renal disease patients)



Source: HES APC Apr 17 - Mar 18

Figure 5 below examines variation in average length of stay for patients following adrenal resection and explores whether this relates to volume of procedures and whether or not they were carried out using minimal access techniques. There is, again, significant variation (approximately seven days between the highest and lowest average) in length of stay following this type of surgery, which may well be unwarranted. The funnel plot does not evidence a significant link between volume of procedures and length of stay for adrenal resections, suggesting other factors are involved in deciding when to discharge. It is also possible that small numbers, casemix and prolonged stays due to complications skew the data. The following can, however, be noted for adrenal resection:

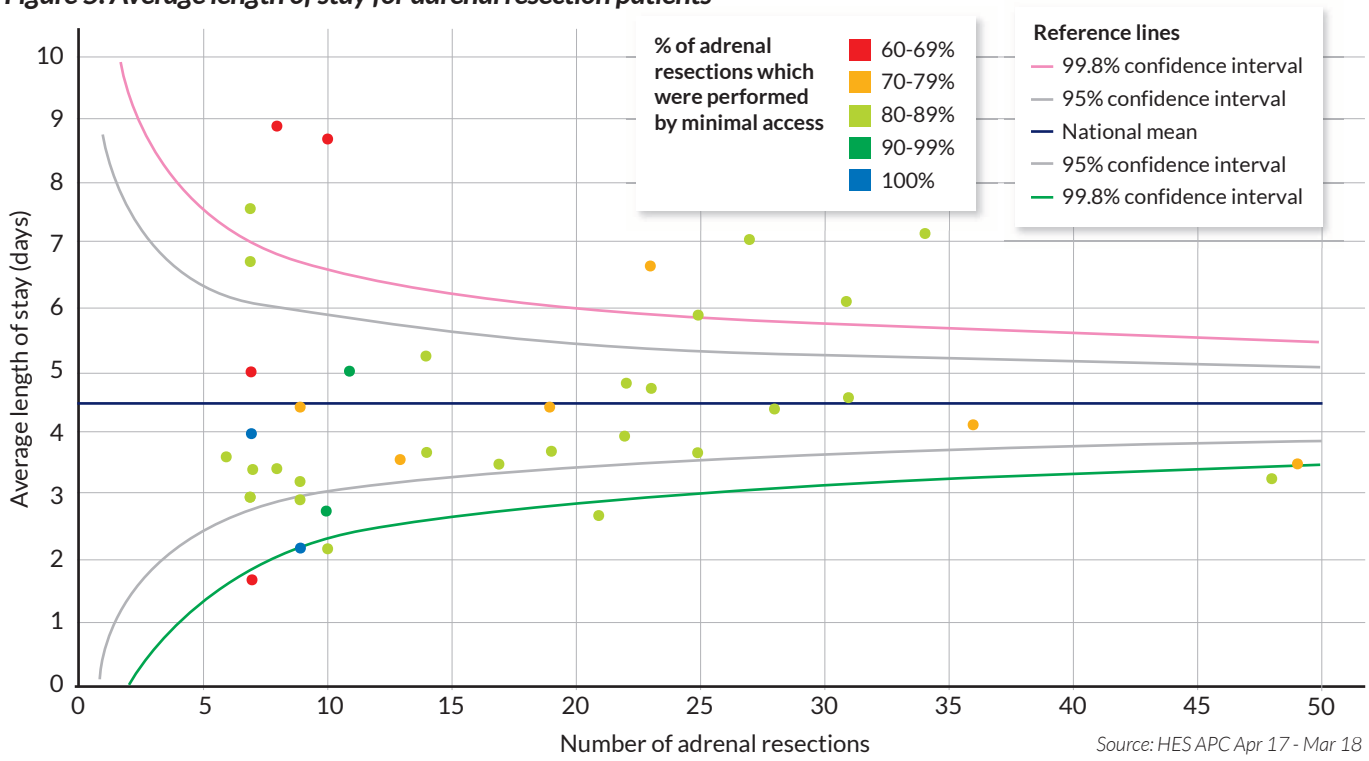
- three of the four highest-volume centres achieved average lengths of stay of less than five days.
- most providers do 80–89% of adrenal resections via minimal access.
- the two most significant outliers with lengths of stay higher than the 99.8% confidence interval both performed less than 70% procedures using minimal access

[21] *An example of management of post-operative hypocalcaemia has been published by BAETS, which may help support earlier discharge: www.baets.org.uk/wp-content/uploads/BAETS-Post-op-Hypocalcaemia-Guidance.pdf*

Use of minimal access does not appear to be the main driver of lower length of stay in this data. There are five providers doing less than 79% via minimal access that have lower than average lengths of stay and five providers doing less than 79% via minimal access with higher than average lengths of stay. We believe this may be due to a lack of previous benchmarking and audit and may also reflect suboptimal pathways, especially with regard to perioperative care and discharge planning.

All adrenalectomies must be discussed at an MDT meeting, where a target for discharge should be set and any additional postoperative endocrine testing (for example a short synacthen test) can be done in a timely manner.

Figure 5: Average length of stay for adrenal resection patients



Source: HES APC Apr 17 - Mar 18

CASE STUDY

Adrenal pathways using hub and spoke model

Leeds Teaching Hospitals NHS Trust

Complex adrenal surgery requires experienced surgeons operating on a suitable volume of patients. Adrenal pathways are not always streamlined, which can affect referral-to-treatment times and reduce the efficiency of postoperative follow-up. Individual services may be overwhelmed, and outcomes affected, if patients are not managed appropriately.

Hub and spoke pathways

The unit at Leeds Teaching Hospitals NHS Trust established an MDT to take adrenal referrals from nearby trusts. Before patients attend the consultant clinic they are triaged by a specialist registered nurse and booked into a day case clinic where their tests and additional imaging is conducted by nurse specialists. Test results are discussed by the MDT within two weeks, resulting in discharge or appointment to discuss results at an endocrine or surgical clinic. In addition, a postoperative plan for surgical patients is agreed at the MDT to optimise length of stay. Good links with the spokes (and mobile specialist nurses) facilitate follow-up appointments local to patients where indicated.

Results

- Efficient adrenal pathways improve referral-to-treatment times.
- Surgical expertise is concentrated at the hub, ensuring complex surgery is undertaken by the most experienced surgeons in a multidisciplinary setting.
- More routine work and follow-up is distributed across the spokes.

In Practice – Emergency hydrocortisone injections for adrenal insufficiency.

We found that 33% of departments did not supply emergency hydrocortisone kits together with a needle and syringe for rapid administration. This is essential for the safety of patients. Endocrine departments (not the GPs) should supply hydrocortisone kits that include a needle and syringe to ensure safety and timely administration in an emergency.

CASE STUDY

Co-led management of parathyroid pathways

Hull University Teaching Hospital NHS Trust

The team at Hull wanted to improve clinical outcomes and patient experience for people with parathyroid disease. Working jointly with the endocrinology and ear nose throat (ENT) teams, minimising hospital visits and providing a seamless experience across the specialties.

Joint clinics

Integrated cross-division working between endocrinologists and ENT consultants was established in a joint clinic for thyroid and parathyroid disease. A referral assessment service streamlines new referrals to the joint clinic where indicated, or a general endocrine clinic. This pathway for the management of parathyroid disease eliminates the need for cross referrals between the two specialties and enhances shared decision making between patient, endocrinologist and surgeon.

Results

The trust has the option to provide a one-stop service, via a 'straight-to-test' pathway enabling patients to be assessed by DXA bone density imaging which is available during the same visit. The pathway has an excellent record in patient safety and has particularly robust protocols around post-operative testing and proven results of calcium normalisation in 97% of patients.

To note

- The clinic's referral assessment service ensures appropriate cases are channelled to surgery and surgeons that perform significant volumes to ensure a high level of experience and expertise.
- Patient choice and shared decision making are maintained throughout the pathway.
- Registrars from both specialties benefit from shared learning, gaining experience and exposure they could not get elsewhere in the training programme.

CASE STUDY

Triaging of referrals through Choose and Book

Portsmouth Hospitals NHS Trust

When the Choose and Book programme was implemented nationally, the endocrinology department at Portsmouth Hospitals NHS Trust noted an increase of inappropriate clinic bookings. These unnecessary bookings took up clinic spots and negatively impacted those requiring early assessment and the capacity of sub-specialty and MDT clinics.

Review and triage of referrals

Portsmouth Hospitals NHS Trust has since allocated an individual consultant with the role of review and triage of all appointments booked through the Choose and Book system. Using this process, the department is able to ensure patients are allocated to the correct clinic, first time. For patients without significant endocrine disease their referral is converted to Advice and Guidance, with responses provided within 48 hours.

Results

- Despite an increase in referrals waiting lists have been maintained and in some cases slightly reduced.
- Patients are able to receive appropriate first-line investigations in primary care before their clinic appointment.
- Primary care colleagues are complimentary of service and the timeliness of responses.

To note

- The activity occupies approximately 1 PA per week (for a 5 consultant, 3 SpR, 2 ESN service) and results in alternate follow-up arrangements for approximately 1:5 referrals made.

CASE STUDY

Streamlined referral for urgent non-cancer patients

Bolton NHS Foundation Trust

Patients with serious non-cancerous endocrine conditions requiring urgent surgery often wait for a prolonged period of time. There is no system to ensure that patients with serious non-cancerous endocrine conditions requiring urgent surgery are prioritised in the same way as patients with a malignancy.

Urgent non-malignant patient category

Bolton NHS Foundation Trust has implemented a new category on their surgical forms, urgent non-malignant. This ensures these patients are not overlooked, and are prioritised alongside malignant cases. All patients are vetted before they attend clinic, ensuring this is highlighted at an early stage and enabling a better outcome for the patient.

Results

- Patients with conditions such as Graves' disease or parathyroid adenoma can now be prioritised on operating lists.
- Patients with urgent non-malignant cases have been seen earlier, rather than waiting with other non-urgent cases.
- Cases for urgent cancer have only been minimally affected.

To note

- The trust operates a streamlined referral system with close endocrine and MDT working.
- Consultants with a special interest look after patients in their areas of expertise to optimise patient care.

Recommendations

Recommendation	Actions	Owners	Timescale
1. Reduce unnecessary duplication of diagnostic tests to streamline initial referral and avoid wastage. Appropriate information sharing is an essential part of the provision of safe and effective care.	**a** GIRFT and the Society for Endocrinology to provide guidance on which diagnostic tests are appropriate to be carried out or commissioned by GPs prior to referral to secondary or specialist care, and which should follow or be conducted at an initial outpatient visit or arranged between referrer and referee.	GIRFT, Society for Endocrinology	12 months
	b GIRFT to ensure guidelines on diagnostic testing at appropriate point in patient journey inform Choose and Book criteria.	GIRFT	12 months
	c In line with new NHS Digital's Data and Technology Standards Framework, providers should look to improve digital interoperability to enable clearer visibility in both directions on the electronic patient record around which tests have been conducted/ requested, as well as any which follow after diagnosis and treatment.	Trusts	2 years
2. Expedite prompt referral to specialised care where indicated (in this recommendation we support the work of the NHS Neuroscience Transformation Programme and the work currently being undertaken by NHS England to rewrite the specification for specialised adult endocrinology services).	**a** GIRFT to ensure proposed list of endocrine conditions which indicate a need for specialised care are fed into NHS England review of specifications for specialised endocrinology services.	GIRFT	6 months
	b Trusts to declare compliance with service specifications for treating these conditions through the Quality Surveillance Information System (QSIS).	Trusts	For immediate action
	c Trusts to agree referral and repatriation criteria and record these consistently to ensure that referrals between centres include a clear rationale for the need for specialist input in a standardised way.	Trusts	12 months
3. Deliver networked service models so that patients can be referred to the most appropriate surgeon and the correct level of care.	**a** Trusts to establish service-level agreements to facilitate and deliver recommended network service arrangements and models (see recommendation 8) including for: i. treatment of medullary thyroid cancer; ii. adrenalectomies (and to ensure within each network there is a hub for adrenal cancer and phaeochromocytomas); iii. pituitary surgery.	Trusts	For substantial progress within 1 year

Recommendation	Actions	Owners	Timescale
4. Consider options to accelerate urgent treatment for patients with serious non-cancer endocrine conditions.	**a** GIRFT to work closely with NHS England and trusts to review referral pathways for life-threatening endocrine conditions or conditions which have risks of major complications (listed below) to ensure that patients can access urgent treatment without unnecessary delay once diagnosis is confirmed: i. phaeochromocytoma; ii. severe hypercalcaemia; iii. severe pressure symptoms of enlarged thyroid; iv. Cushing's syndrome;	GIRFT, NHS England	12 months
5. Ensure that where clinically appropriate, lengths of stay for surgical procedures are reduced.	**a** Trusts to review their patient pathways with a view to achieving the following targets for elective admissions:[22] i. 90% of patients having parathyroid surgery for primary hyperparathyroidism to be discharged with zero night stay (day case); ii. 90% of patients undergoing thyroid lobectomy to be discharged with no more than one night's stay; iii. 90% of patients undergoing total thyroidectomy to be discharged with no more than two nights' stay.	Trusts	For immediate consideration and action within 6 months

[22] *See Appendix 3 for a table summarising BADS-recommended lengths of stay for the procedures listed.*

Appendix to recommendation 2: Conditions indicating referral to specialised endocrine services[23]

Specialised thyroid conditions (cancer element is covered in the Cancer: Head and Neck (Adult) Service Specification)

- Thyroid ophthalmopathy
- Severe and complex thyroid conditions

Specialised metabolic bone and mineral calcium/bone conditions

- Complex or severe presentation of hyperparathyroidism (for example with bone complications, failed initial neck exploration, recurrent disease, difficulties with localisation, familial cases and hyperparathyroidism in pregnancy)
- Complex problems of calcium/phosphate handling (including familial calcium/ phosphate disorders)
- Complex osteoporosis (adult osteoporosis associated with high fracture risk where assessment and/or therapeutic decisions are/will be significantly influenced by contraindications or cautions to therapies and/or either skeletal and non-skeletal comorbidities)
- Osteogenesis imperfecta (and other syndromes of high fracture risk)
- Hypoparathyroidism
- Fibrous dysplasia/McCune Albright Syndrome
- Sclerosing bone disorders (including complex Paget's disease)

Specialised reproductive conditions

- Turner's syndrome
- Endocrine-related male infertility
- Virilising disorders
- Disorders of gonadal and sexual development
- Intersexual states and genetic malformation
- Complex fertility treatments including recombinant gonadotrophins and clomiphene

Specialised Adrenal Conditions

- Primary adrenal failure (at diagnosis)
- Congenital adrenal hyperplasia
- Adrenal Cushing's syndrome
- Bilateral adrenalectomy for adrenocorticotropic hormone (ACTH) -dependent Cushing's syndrome
- Hyperaldosteronism
- Phaeochromocytoma
- Virilising adrenal lesions
- Complex adrenal conditions in pregnancy
- Adrenocortical carcinoma
- Other adrenal tumours

Pituitary and hypothalamic diseases

- Non-functioning adenoma
- Acromegaly
- Cushing's disease
- Macroprolactinoma

[23] *Clinical Reference Group for Endocrinology updated 2019 NHS England.*

- TSHoma (thyroid stimulating hormone-producing pituitary adenoma)
- Gonadotrophinoma
- Para-sellar tumours
- Infiltrative and granulomatosis, hypothalamo-pituitary disease
- Craniopharyngioma
- Hypothalamic tumours
- Congenital and acquired anterior and posterior hypopituitarism including complex growth hormone deficiency
- Pituitary surgery

Neuroendocrine tumours

- Carcinoid syndrome
- GI pancreatic neuroendocrine tumours
- Insulinoma
- Gastrinoma
- Glucagonoma
- Paraganglioma
- Vipomas
- Non-functioning pancreatic neuroendocrine tumours
- Neuro-endocrine tumours outside the gut
- Familial syndromes involving neuroendocrine tumours

Familial endocrine disorders, for example:

- Multiple endocrine neoplasia syndromes
- Von Hippel Lindau disease
- Familial paraganglioma syndromes
- Familial medullary carcinoma
- Familial hyperparathyroidism
- Paediatric endocrine conditions in endocrinology
- Transitional endocrinology

Ensuring endocrinologists and surgeons record and know their numbers, outcomes and complication rates

There are two key aspects to this theme. One is the importance of auditing numbers and clinical outcomes. An effective audit regime positively informs population health, improves patient outcomes and can promote innovation. Most crucially, an unaudited service offers no assurance that the care provided is safe and effective.

The second is the broader issue of what types of outcomes should be recorded. Many HQIP consultant-level publications tend to focus on 30-day mortality rates with less emphasis on catastrophic post-operative outcomes that can be life-changing for patients. Mortality attributable to endocrine surgery is uncommon. At present only the UKRETS audit captures data on post-operative events immediately following surgery and later at follow-up. This brings into focus the potentially life-changing side effects of surgery on the thyroid, parathyroid, and adrenal glands. A similar audit is needed to capture this data for pituitary surgery.

This theme also relates closely to the need, covered in detail in the next section, to concentrate key complex procedures among fewer surgeons in order to ensure that both individual surgeons, nurses and multidisciplinary teams around them have the knowledge and skills to ensure the best patient outcomes.

The importance of submitting data for audit

There is a wide range of emergency readmissions, lengths of stay and complication rates between trusts. During our visits we also found that many surgeons undertaking endocrine procedures do not record, and therefore do not know with any certainty, their outcomes and complication rates.

The document 'Good Surgical Practice'[24] published by the Royal College of Surgeons of England builds on advice from the GMC's publication, "Good Medical Practice' and offers the following recommendation: '*Engage in quality assurance processes and quality improvement activities, including participation in national and local audit, measuring validated local outcome data, peer review, multidisciplinary meetings and morbidity and mortality meetings.*'

Without adequate audit and benchmarking, poor practice and outcomes can continue undetected. There are substantial shortfalls in recording the outcomes of adrenalectomy and neck surgery (thyroidectomies and parathyroidectomies) and surgery on the pituitary gland. This data is vitally important for audit, as well as for the purposes of commissioning and to support patient choice.

UKRETS is considered by HQIP to be a mandatory audit for thyroid, parathyroid and adrenal surgery and meets NICE cancer service guideline 6 for head and neck cancers.[25] In common with some other national audits it is funded by subscription. This is currently through BAETS and costs each surgeon less than £1 per week. Surgeon volumes and some outcome measures are put into the public domain by BAETS on their website. Individual surgeons can also compare their results to outcomes recorded in the database, for example for the purposes of appraisal.

The need to record outcomes

Complications must not go unreported and unaddressed. Regular local reviews and audits of work that surgeons and their teams undertake should be routine and feed into the national audit. Outcomes must be reviewed constructively and in a timely manner to ensure steps are taken promptly to address any problems of outcome or underperformance.

Post-operative complications can be life-changing for patients. To give one relatively common procedure as an example, there is a risk that an apparently successful total thyroidectomy will lead to permanent hypoparathyroidism and lifelong dependency on high-dose supplements of vitamin D and calcium. If poorly managed, this in turn can result in renal stones or even kidney failure – the patient's life expectancy and quality of life may have been made worse rather than better.

[24] *Royal College of Surgeons (no date), Good surgical practice: A guide to practice (section 1.1), www.rcseng.ac.uk/standards-and-research/gsp/domain-1/1-1-develop-and-maintain-your-professional-performance/*

[25] *National Institute for Health and Care Excellence (2009), Improving outcomes in head and neck cancers (CSG6), https://www.nice.org.uk/guidance/csg6*

In Practice – Management of postoperative hypocalcaemia

We found some departments use a flow chart protocol to manage hypocalcaemia following thyroidectomy. A written protocol provides a clear process that all members of the multidisciplinary team can reference and apply consistently. This is essential for the safety of patients and the improvement of outcomes. See Appendix 5, on page 97, for an example flow chart.

Similarly, there is a risk of permanently damaging the recurrent laryngeal nerve while operating on the thyroid or parathyroid. This can bring about profound changes in voice quality that are not only distressing for patients but can affect employment. Post-operative bleeds are also a risk with thyroid surgery and parathyroid surgery, and although there is a recommended thyroid bleed protocol on the BAETS website,[26] we noted that not all trusts display or follow this. In fact, of 90 trusts that responded when asked, 43 (47.8%) said they do not have a thyroid bleed protocol in place. We have advised them to implement one.

It is not justifiable to refer someone to a surgeon who is unsure how often their patients experience such complications. Neither is it acceptable for these patients to be managed in an environment where staff do not have easy access to protocols to manage these complications.

Table 3: Examples of possible negative outcomes (in addition to other general complications) after endocrine neck surgery

Organ	Condition	Procedure/treatment	Possible negative outcomes for audit
Thyroid	■ Graves' disease ■ Goitre with pressure symptoms ■ Diagnostic and therapeutic surgery for thyroid cancer	Thyroidectomy	■ Temporary hypocalcaemia which may delay discharge ■ Permanent hypoparathyroidism ■ Breathlessness and difficulty swallowing with recurrent laryngeal nerve damage ■ Tracheostomy after bilateral nerve damage
Parathyroid	Hyperparathyroidism	Surgery	■ Adenoma not found or insufficient parathyroid tissue resected in hyperplasia – condition unchanged ■ Too many parathyroids removed/damaged – risk of hypoparathyroidism

Next steps

For these reasons we recommend that all necessary steps be taken to ensure surgeons and endocrinologists submit their data to the relevant national databases. We also feel that further consideration should be given to publishing openly some outcomes in more detail, i.e. outlining known outcome risks for certain procedures and recording the occurrence of these, at least at a unit level. In line with the National Clinical Improvement Programme (NCIP), surgeon-level data should be used in appraisal in combination with a robust outlier policy. The advantages for patients of this approach are obvious and there are also positive implications for litigation costs.

[26] *British Association of Endocrine and Thyroid Surgeons (BAETS), Management of post-operative haemorrahage in thyroid and parathyroid surgery, www.baets.org.uk/management-of-post-operative-haemorrhage/*

CASE STUDY

Management of patients with post-operative hypoparathyroidism

University Hospitals of Derby and Burton NHS Foundation Trust

Post-operative hypoparathyroidism is a common complication following neck surgery such as thyroidectomy. Patients who develop hypoparathyroidism require close follow-up, with early interventions offering improved patient outcomes and better quality of life. Proactive management, following agreed protocols and pathways are a key driver for improvement in these cases.

Local guidelines for post-operative hypoparathyroidism

In October 2018 University Hospitals of Derby and Burton NHS Foundation Trust introduced guidelines for the management of post-operative hypocalcaemia following neck surgery. The guideline includes a step-by-step protocol for the surgical team to identify and manage post-operative hypocalcaemia. The guideline also includes a patient pathway for onward referral to endocrinology for patients prescribed calcium and vitamin D. To ensure no patient 'falls through the cracks' a record of hypoparathyroid patients is kept and proactively monitored by endocrine specialist nurses at the trust.

Results

- Patients and staff alike are satisfied with the streamlined pathway for monitoring patients, the reduction in delays and follow up of missed patients.
- Dedicated new patient slots have been allocated for patients with post-operative hypoparathyroidism.

To note

- The main challenge was limited nurse capacity; this was mitigated by a successful business case to provide increased hours for an endocrine specialist nurse.

Recommendations

Recommendation	Actions	Owners	Timescale
6. Improve audit and availability of data relating to all endocrine operations.	**a** All surgeons carrying out thyroid surgery, as well as those carrying out parathyroid or adrenal surgery should participate in the British Association of Endocrine and Thyroid Surgeons (BAETS) electronic UK Registry of Endocrine and Thyroid Surgery (UKRETS) to allow for accurate auditing of services.	Trusts, BAETS	For immediate action
	b Trusts to include data capture for national audit as part of job descriptions and job planning for consultants, with time allocated as required.	Trusts	Immediate and ongoing
7. Agree clearer definitions and protocols for surgical complications.	**a** GIRFT to work with patient groups and professional societies to review and agree clearer definitions of surgical complications e.g. deficient calcium post thyroidectomy, damage to the recurrent laryngeal nerve post-thyroidectomy and hypopituitarism post hypophysectomy (removal of the pituitary gland).	GIRFT	6 months
	b GIRFT to work with professional societies to share exemplar protocols for conditions where surgery involves a known risk of life-changing complications or post-operative issues, e.g. thyroid bleed protocols.	GIRFT	12 months

Concentrating key procedures among fewer surgeons to avoid low volumes

As a result of our deep-dive visits, questionnaire data and further analysis, we feel there is a clear case for endocrine surgery services to be organised around fewer surgeons doing greater numbers of specific procedures and auditing their outcomes. Our concern is not primarily about the skill of individual surgeons (although this is potentially an issue in a small number of cases), but about overall team competencies.

If the surgical team has sufficient experience, especially in the less common procedures, they will offer a high-quality service overall, nurses will have familiarity with key conditions and post-operative care will be optimised. Where this is not the case, it is likely to result in poorer outcomes along with an increased risk of complications and increased length of stay. These findings are in keeping with the accumulating body of knowledge in peer-reviewed journals that has found outcomes for many surgical procedures have a relationship to individual surgeon and institution volumes.[27] This supports the case for having appropriately trained surgeons available for the recommended procedures to be undertaken in the most appropriate setting with the support of an experienced team.

It is accepted that it is difficult to say with certainty how a surgeon's outcomes are influenced by chance or case selection.

In context: International comparison

In three trusts we visited, a surgeon operates on one case of Cushing's disease (an extremely rare pituitary condition, the treatment for which is removal of the pituitary tumour) per year. This is in no-one's best interests.

In Germany (with a population almost 30% larger than the UK) we understand that there are three centres that perform 80% of cases for this procedure.[28] In the UK there are currently 27 surgeons. We believe this needs to change and that MDTs should refer these patients to busier centres.

Feedback from patient groups is pertinent here. For example, the 2019 Cushing's diagnosis and treatment survey asked 'If you had to choose between being seen locally or travelling to a surgeon who did many more pituitary operations than the local one, which would you choose?' Over 82% of respondents said they would choose to travel further for a more experienced surgeon.[29] Surgery for Cushing's disease requires close teamwork between endocrinologists, interventional and diagnostic radiologists, nurse specialists, oncologists and surgeons. It should be the focus of national audit to inform high quality data that encompasses all outcomes measures, complications and patient-reported outcomes.

Specialist procedures carried out at low volumes

Figure 6 below highlights that a number of non-specialist trusts are doing low volumes of adrenal resection procedures (those in turquoise are doing below our recommended limit), which ideally should be carried out at more specialist units in greater volume. Poor outcomes amongst patients operated on by low-volume surgeons were described from HES data in 2010.[30] Recent HES data shows no significant redistribution of cases to larger centres. This was borne out by our visits. In one-third of the trusts we visited, we recommended the cessation of adrenal surgery or consolidation with an adjacent trust to ensure adequate numbers to provide a safe service. What we found is broken down by procedure type, showing surgeon and trust numbers in Table 4 below.

[27] *For example, Palazzo, F., Dickinson, A., Phillips, B. et al. (2016), Adrenal surgery in England: Better outcomes in high-volume practices, Clinical Endocrinology 85: 17–20, https://onlinelibrary.wiley.com/doi/abs/10.1111/cen.13021;. Casanueva, F. F., Barkan, A., Buchfelder, M. et al. (2017), Criteria for the definition of pituitary centers of excellence (PTCOE): A Pituitary Society Statement, Pituitary 20: 489–498, https://link.springer.com/article/10.1007%2Fs11102-017-0838-2; Honneger, J. and Grimm, F. (2018), The experience with transsphenoidal surgery and its importance to outcomes, Pituitary 21: 545–555, https://link.springer.com/article/10.1007/s11102-018-0904-4;*

[28] *Personal communication, Prof Dr Michael Buchfelder.*

[29] *The Pituitary Foundation, Cushing's diagnosis and treatment survey, 31 October 2019.*

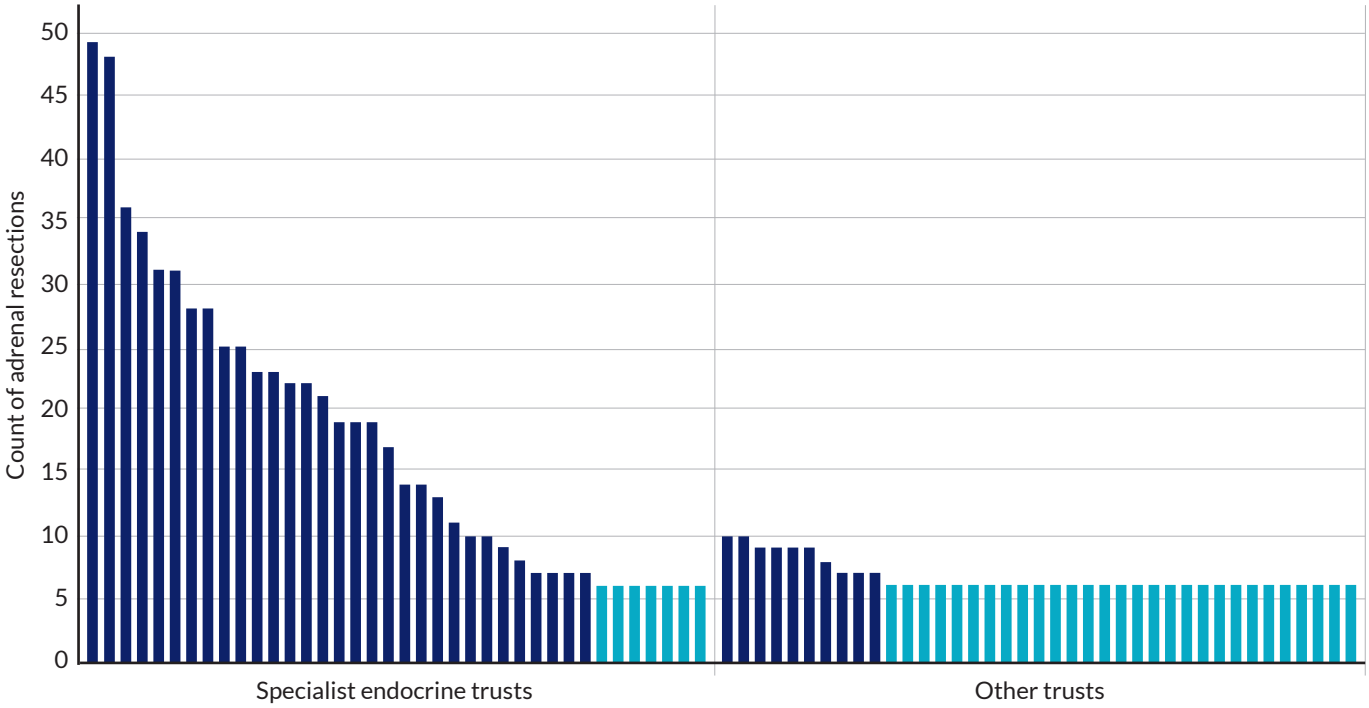
[30] *El-Dhuwaib, Y. and Lansdown, M. (2010), Adrenalectomy in England: Most are done by surgeons who do less than 5 a year, Br J Surg, 97(S2): 20.*

Table 4: Adrenal surgery below our recommended limits

	Adrenalectomies	Cancer adrenalectomies	Phaeochromocytomas
Recommended no.	**6 or above**	**20 or above**	**20 or above**
No. of surgeons doing below recommended no. of procedures	48	64	19
No. of trusts with surgeons doing below recommended no. of procedures	23	36	19

Related to adrenal resections is the process of adrenal vein catheterisation for adrenal venous sampling (AVS). Venous sampling is a diagnostic procedure that uses imaging guidance to insert a catheter into a specific vein and remove blood samples for laboratory analysis. Abnormal levels of certain substances in the blood may indicate the presence of disease in the organ or tissue that produces them. Adrenal and petrosal vein sampling (also known as inferior petrosal sinus sampling or IPSS, where the veins draining from the pituitary gland are catheterised) are used in endocrinology to diagnose Conn's syndrome and Cushing's disease, respectively. Since both are technically demanding and relatively rarely undertaken, we would recommend that that they be done only in units with the appropriate expertise, to be agreed between endocrinology departments and radiology networks, an approach that is advocated in the recently published *Transforming Imaging Services in England*.[31]

Figure 6: Total adrenal resections by trust



Source: HES APC Apr 17 - Mar 18

[31] *NHS England and NHS Improvement (2019), Transforming imaging services in England – A national strategy for Imaging Networks, https://improvement.nhs.uk/resources/transforming-imaging-services-in-england-a-national-strategy-for-imaging-networks/*

Adrenal surgery is spread across too many trusts. In the interest of patients, this surgery should be concentrated in fewer trusts to allow better specialisation which should lead to better outcomes and shorter lengths of stay. There are published guidelines for the management of adrenal tumours agreed by all the relevant specialties. It is disappointing and has implications for quality of care that these guidelines are not being followed.

Improving adrenal surgery

A previously published analysis of HES data recommended individual surgeon workloads of at least six adrenalectomies per year, but we believe that such low volumes do not allow the development of specialised services. All patients undergoing adrenal surgery should be discussed in a properly constituted MDT meeting at least every two weeks before and after surgery.[32] A network model for adrenal surgery should be developed working towards units operating on 20+ patients per year. Within each network should be one hub for phaeochromocytomas based in a hospital with specialist endocrinology. Similarly, patients with suspected adrenal cancer should be treated in a limited number of centres co-located with access to specialist surgical services, including cardiothoracic and hepatobiliary surgery. High-quality surgery is of the utmost importance as, without a clear resection margin, outcomes in terms of life expectancy are very poor. The role of specialist oncology and/or an endocrinologist who is expert in adrenal cortical cancer is important, especially for the supervision of treatment with mitotane.

Furthermore, in order to make significant progress with advancing treatments, it is important to participate in clinical trials, and these are more likely to take place in centres with larger numbers of cases. In due course, supra-regional centres for the treatment of adrenal cortical carcinoma could be considered by NHS England.

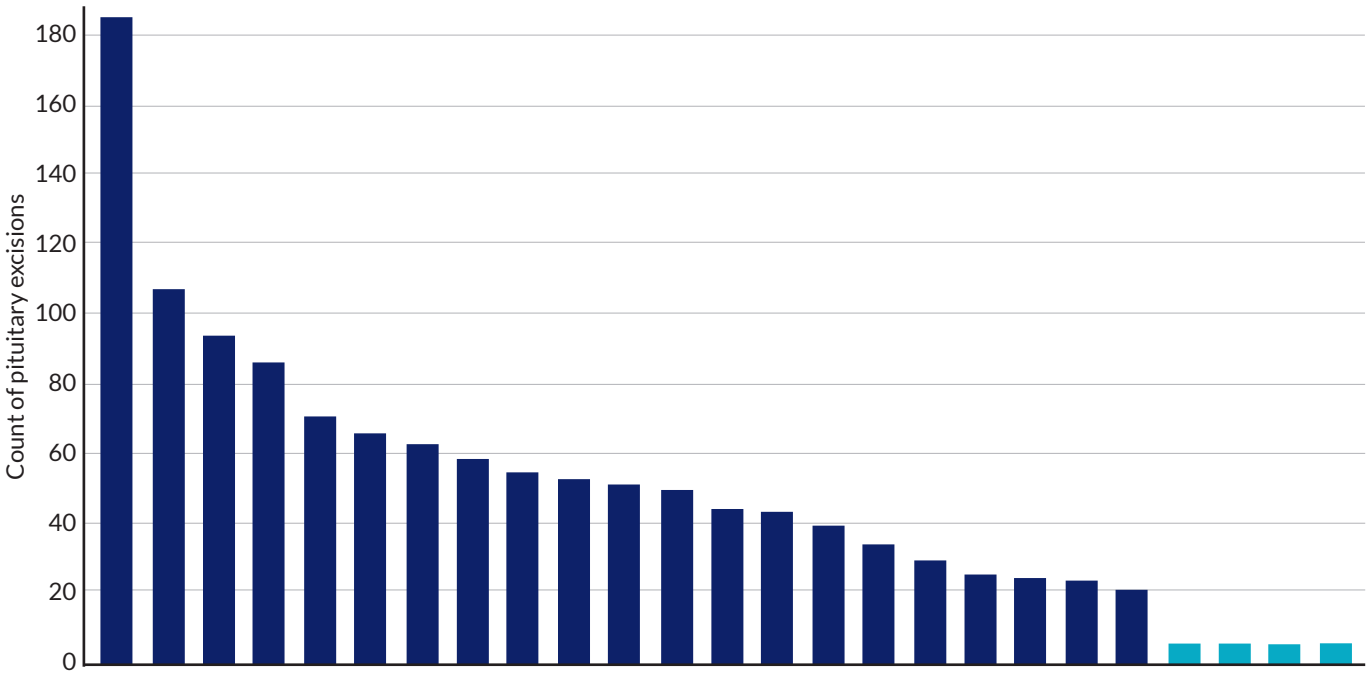
Anticipating the adrenal cancer surgery strategy

The adrenal cancer strategy is being designed to optimise and rationalise care for patients with this condition by eliminating the need for radio or chemotherapy. The focus on surgery means that there will be an increasing need for skilled adrenal surgeons who are able to remove entire tumours. This entails concentrating procedures in a limited number of surgical centres nationally to allow the development of expertise.

Figure 7 below, similar to Figure 6 but for pituitary excisions, shows several trusts doing very few procedures and supports our view that these should only be carried out at a few specialist centres, given the small number of procedures carried out per year vs. the high level of expertise required do them. Further research/investigation is required, such as through both national or local audit to build an evidence base to determine a minimum volume for pituitary surgery. The trusts in turquoise are performing numbers below what we would consider acceptable.

[32] *Palazzo, F., Dickinson, A., Phillips, B. et al. (2016), Adrenal surgery in England: Better outcomes in high-volume practices, Crin Endocrinol (Oxf), July, 85(1): 17–20. DOI: 10.1111/cen.1321. Epub 2016 Feb 15, www.ncbi.nlm.nih.gov/pubmed/26776382*

Figure 7: Total of pituitary excisions by trust[33]



Source: HES APC Apr 17 - Mar 18

Trusts should ensure the most accurate coding for pituitary surgery. Excision of a lesion, such as for acromegaly or Cushing's should be coded as B04.1 excision of lesion of pituitary gland. It should not be from the B01.- category which is excision of the pituitary gland. For example, B01.2, which is transsphenoidal hypophysectomy, would be inaccurate and should not be used.

There are currently 23 centres in England carrying out pituitary surgery. We have collected data on numbers of outcomes of pituitary surgery. Our visits revealed that neurosurgeons carried out the majority of hypophysectomies. In three units these operations were carried out by trained ENT surgeons.

We found variation in outcomes for excision of pituitary lesions, self-reported by trusts. The cure rate for microadenomas causing acromegaly varied from 50 to 100% and for microadenomas in Cushing's a wider range of 0 to 100%. This level of variation is far too wide.

[33] *Note that this chart covers pituitary excisions rather than pituitary surgery in general.*

Improving pituitary surgery

ENT surgeons should operate jointly with neurosurgeons. The Society of British Neurological surgeons (SBNS) recommends one lead surgeon operating on all the functioning pituitary tumours. This was the case in 15 of the 23 departments we visited.

All patients with pituitary tumours should be discussed at the weekly or fortnightly MDT meeting (currently 19/23 do this). Endocrinologists in the pituitary MDT should have a special interest and expertise in pituitary disease. Special infrastructure, e.g. inferior petrosal sinus sampling, should be available in pituitary specialist departments (currently 21/23).

The SBNS recommends ten pituitary operations per surgeon per year. Endocrinologists consider that this should be higher: 20–25 surgeries per surgeon per year, aspiring to 50 per department per year. These higher figures are associated with improved outcomes and decreased complication rates.[34]

Departments with lower surgical volumes should establish joint working for functioning tumours to optimise numbers and thereby improve outcomes and lower complication rates.[35] The Specialised Endocrinology Services (Adult) Quality Dashboard will deliver data on the outcomes of pituitary surgery,[36] which will further inform clinical practice.

For pituitary/neurosurgical work we hope the proposed minimum numbers will increase in the pathway currently under review by the SBNS supported by the Pituitary Surgery Clinical Working Group. This is part of a national programme led by NHS England and NHS Improvement and will be available for sharing in 2020. The programme recommends a networked approach. Conditions such as acromegaly and Cushing's disease fall within a second workstream reviewing delivery of low and ultra-low volume neurosurgery.

The relationship between surgical volumes and outcomes

Figure 8 below demonstrates the relationship between the number of procedures (in this case thyroidectomies) carried out at a provider level and the quality of outcomes (in this case, readmissions at or before seven days after surgery). The chart groups total activity as a distribution for providers depending on how many procedures were delivered.

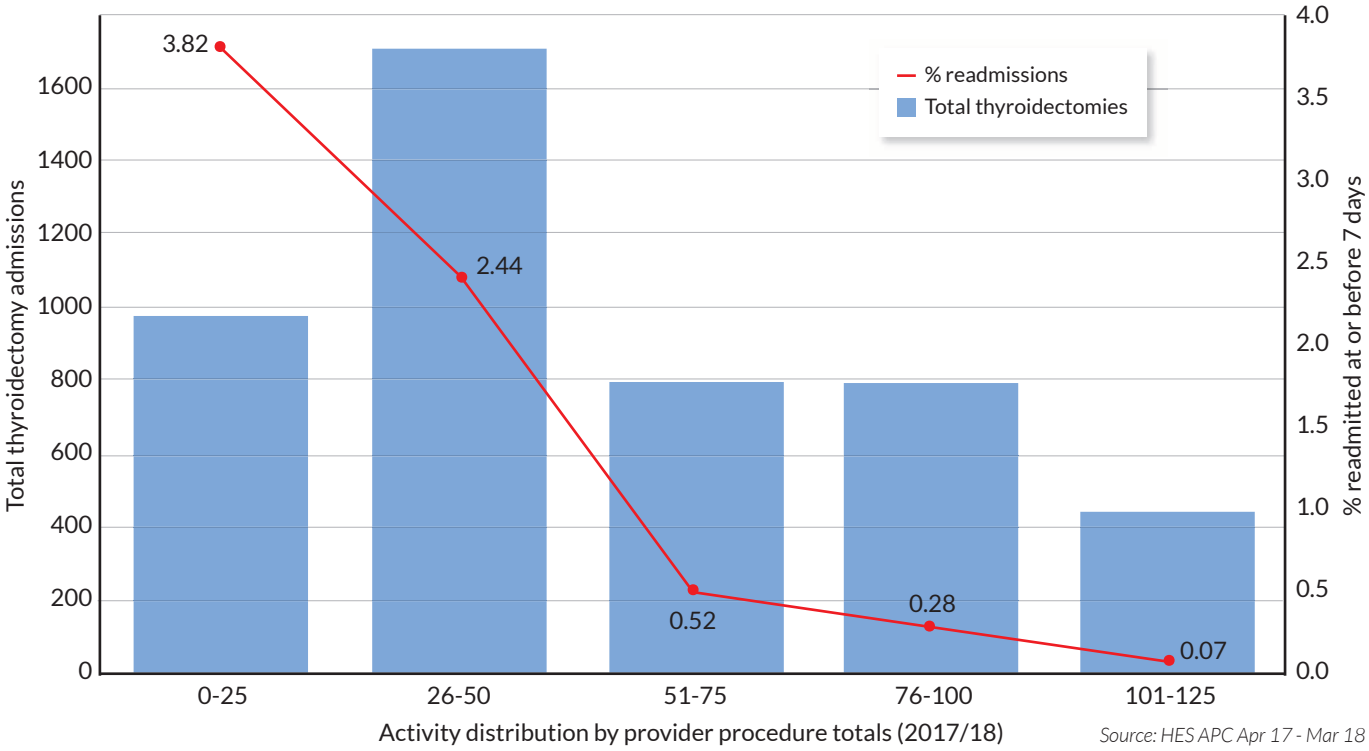
Although we could not show that any one provider was a statistical outlier from the data we had (largely because this is difficult with small numbers), when aggregated to show total activity distribution in this way, there appears to be a fairly clear link between volume of surgery carried out at a provider and the percentage of readmissions.

[34] *McLaughlin, N., Laws, E. R., Oyesiku, N. M. et al. (2012), Pituitary centers of excellence, Neurosurgery 71: 916, www.ncbi.nlm.nih.gov/pubmed/22902334; Barker, F.G. 2nd, Kilbanski, A. and Swearingen, B. (2003), Transphenoidal surgery for pituitary tumors in the United States, 1996–2000: mortality, morbidity and the effects of surgeon volume, endocinol metab. Oct, 88(10): 407–419, www.ncbi.nlm.nih.gov/pubmed/14557445; Petersenn, S., Beckers, A., Ferone, D. et al. (2015), Therapy of endocrine disease: outcomes in patients with Cushing's disease undergoing transsphenoidal surgery: systematic review assessing criteria used to define remission and recurrence, Eur L Endocrinol. June 172(6): R277–239, https://www.ncbi.nlm.nih.gov/pubmed/25599709; Casanueva, F. F., Barkan, A., Buchfelder, M. et al. (2017), Criteria for the definition of pituitary centers of excellence (PTCOE): A Pituitary Society statement, Pituitary 20:489–98, https://link.springer.com/article/10.1007%2Fs11102-017-0838-2; Honneger, J. and Grimm, F. (2018), The experience with transsphenoidal surgery and its importance to outcomes, Pituitary 21:545–555, https://link.springer.com/article/10.1007/s11102-018-0904-4*

[35] *Casanueva, F. F., Barkan, A., Buchfelder, M. et al. (2017), Criteria for the definition of Pituitary Tumor Centers of Excellence (PTCOE): A Pituitary Society statement, Pituitary 20: 489–498,*

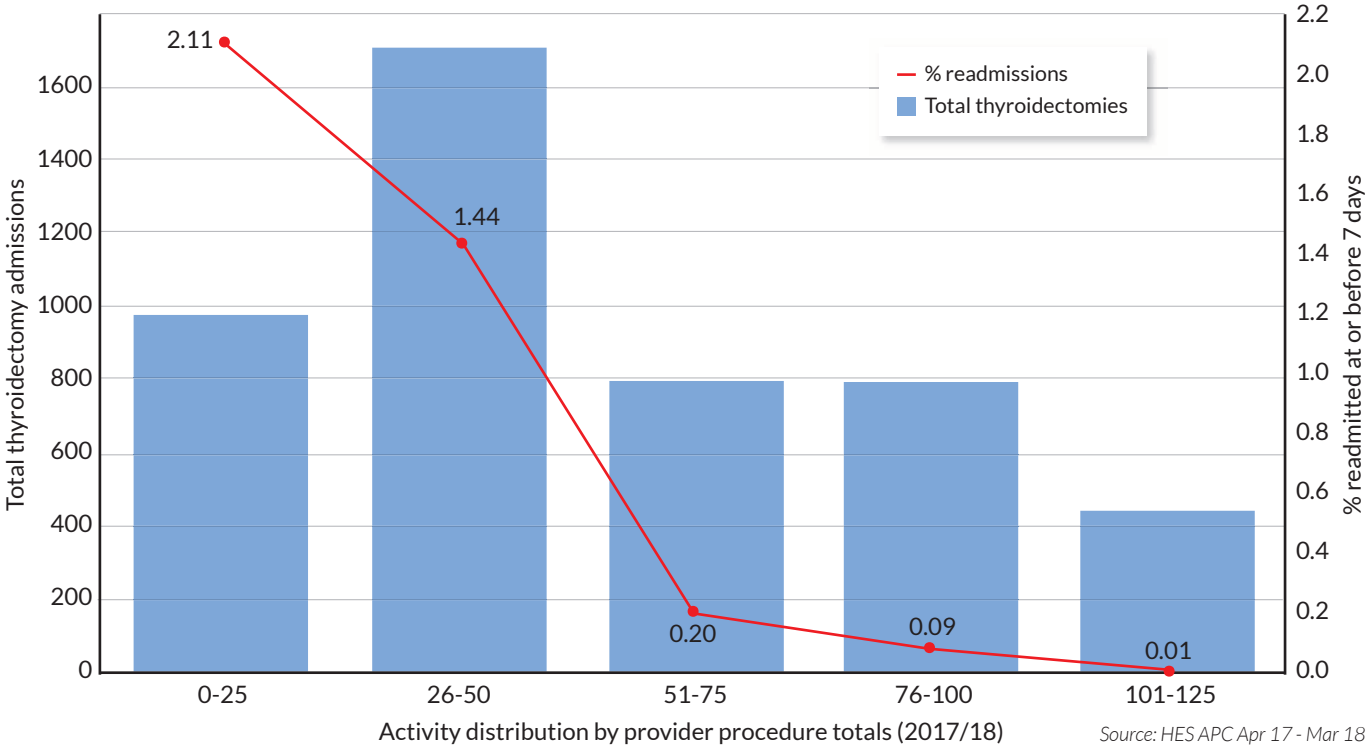
[36] *www.england.nhs.uk/commissioning/spec-services/npc-crg/spec-dashboards/*

Figure 8: Total thyroidectomy readmissions at or before seven days



Source: HES APC Apr 17 - Mar 18

Figure 9: Total thyroidectomy readmissions for hypocalcaemia at or before seven days



Source: HES APC Apr 17 - Mar 18

Improving thyroid surgery

A national endocrine surgery specification should be established. Trusts and commissioners for STPs or groups of CCGs should decide how it should be implemented in their region with regard to specialist and general endocrinology services, surgeons and numbers of procedures. It seems reasonable to us that the present recommendation from BAETS that thyroid surgery should be undertaken by surgeons doing at least 20 cases a year should be implemented immediately. In the longer term, over the next three years or so, services should be organised so that surgeons average 50 or more cases a year in units with at least two surgeons. It has recently been suggested that training in thyroid surgery should take place in centres performing no fewer than 100 cases a year.[37] Such volumes enable surgeons to develop thyroid or endocrine surgery clinics and ensure ward and theatre staff are responsible for thyroid patients on a weekly basis. This ensures patients are seen in a specialist setting. The Joint Committee on Surgical Training should consider allowing general surgeons with an interest in endocrine surgery a period of recognised training in ENT departments with specialist thyroid services and vice-versa.

Medullary thyroid cancer should be managed in cancer centres where there is adequate experience of node dissection and also support from endocrinologists and geneticists familiar with managing families with multiple endocrine neoplasia (MEN). Most other thyroid cancer patients can be managed on a hub and spoke basis with a central thyroid cancer MDT ideally meeting each week.

If evidence is forthcoming subsequently that higher numbers are needed to ensure expertise in thyroidectomy for Graves' disease or hyperparathyroidism, this should be addressed.

Improving parathyroid surgery

There is no existing national recommendation for the number of parathyroid operations, but similar models can be applied to ensure patients are managed by endocrinologists and surgeons who see sufficient numbers of patients each year to maintain expertise. We suggest an indicative number of 50 parathyroid operations at institution level (and 20 per surgeon) a year as a good starting-point. This is in line with the above-mentioned recommendations for training.

> *The issue of low volume surgeons and the outcomes for their patients highlight a situation that can no longer be ignored.*
>
> **Parathyroid UK**

Further research

W. K. Gray (Senior Research Associate, GIRFT Programme) has conducted extensive research using HES data on the relationship between low surgical volumes and quality of outcomes in thyroid surgery specifically.[38] His findings strongly support our own views and we believe the thyroid data to be generally applicable across a range of endocrine procedures. We reproduce Gray's work in Appendix 2 (see page 86)

[37] *Gimm, O., Barczyński, M., Mitai, R. et al.(2019), Training in endocrine surgery, Langenbecks Arch Surg, 404: 929–944, https://link.springer.com/article/10.1007/s00423-019-01828-4*

[38] *Gray, W. K. (2019), Analysis of data from BAETS UKRETS database on the relationship between surgeon volume and outcomes for thyroid procedures, 2 July and Volume–outcome relationships in total thyroidectomy: Summary of key findings for the national report, 11 July (see Appendix 2).*

Next steps

We recommend that trusts take urgent action to identify who is performing thyroid, adrenal, parathyroid and pituitary surgery. Surgeons should then be asked to collect data over the next year to demonstrate compliance with recommended numbers. Surgeons who refuse to comply with audit should not continue to operate and discussion of numbers should be included in appraisal. Where necessary, an action plan should be put in place. This may involve working with other trusts to allow fewer surgeons to do more cases. In addition we strongly recommend that the complex surgery discussed above should immediately be redirected to appropriate centres, which may also necessitate flow of less complex surgery in the other direction.

While we don't have the data to support these recommendations in relation to paediatric endocrine surgery, we would strongly encourage endocrinologists to refer these patients to specialist endocrine surgeons and trusts that have high-volume experience in managing complex paediatric endocrine cases, rather than to paediatric surgeons who may lack sufficient endocrine experience.

CASE STUDY

East of England videoconference pituitary MDT meetings

Cambridge University Hospitals NHS Trust

The East of England pituitary MDT has been overseeing the care of patients with sellar and parasellar tumours for over 20 years. However, it previously took the form of a monthly face-to-face meeting at which decisions were taken by a small group of clinicians at Cambridge University Hospitals NHS Trust. This meant that members of the endocrine teams in other centres were not directly involved in decisions about their patients.

Region-wide virtual MDT

Videoconferencing technology has been adopted to transform a locally delivered MDT to a region-wide virtual MDT. Most recently the MDT has adopted an NHS-approved platform that allows members to join from their personal laptop or mobile device, thus giving them even greater flexibility.

Results

- Enhanced clinical care with greater collaboration across centres (particularly valuable for patients requiring urgent surgery).
- Buy-in from all centres has increased the standardisation of care.
- Offers a unique opportunity for enhanced training, as trainees from outside the tertiary centre are encouraged to observe and participate in the expert discussion.
- A near normal service, protecting both patients and NHS staff, was maintained during first wave of the COVID-19 pandemic and decisions regarding time-sensitive treatment during this period were taken following discussion with the relevant members of the MDT.

To note

- Local policy and guideline documents were developed collaboratively to ensure region-wide ownership of the pathways and processes.
- The appointment of a dedicated MDT co-ordinator who can work closely with the MDT chairs and lead specialist nurses was essential to effective delivery, ensuring minimum dataset required was met for all scans, test results and visual assessments to be available for the meeting.

Recommendations

Recommendation	Actions	Owners	Timescale
8. Trusts should work collaboratively in networks or amalgamate services to concentrate surgical expertise. Direct patients requiring surgery to appropriately trained surgeons performing the recommended volume of procedures.	**a** Optimise specialist endocrinology care and ensure a safe service is provided, as recommended in national service specifications and international guidelines. In particular:	Trusts, STPs	1 year to develop networks
	i. Centres carrying out very few **adrenalectomies** (under six adrenalectomies per surgeon per year or under 20 if they are operating on patients with adrenal cancer and phaeochromocytoma) should stop doing so. These centres should refer patients to surgeons within their network who perform this procedure at higher volumes.		Immediate
	ii. Centres carrying out **thyroid surgery** should ensure surgeons are carrying out a minimum number of 20 thyroid operations each per annum or that patients are being referred to surgeons within their network who perform these procedures at higher volumes.		Immediate
	iii. Centres carrying out **parathyroid surgery** should ensure surgeons are operating on at least 20 patients per annum or that their patients are being referred to surgeons within their network who perform these procedures at higher volumes.		Immediate
	iv. Centres carrying out **pituitary surgery** should ensure surgeons are operating on 20 patients per annum, aspiring to 50 operations per department per year or their patients should be referred to surgeons within their network who perform these procedures at higher volumes.		Immediate
	b Endocrinology departments should work with regional vascular and radiology networks[39] to optimise numbers regionally and improve success rates of adrenal venous sampling (AVS) and petrosal sinus sampling.	Trusts	6 months
	c GIRFT to work with the NHS pricing team to ensure that commissioning models encourage best practice by only funding adrenalectomies and pituitary surgery where these are carried out at a specialist centre.	GIRFT, NHS pricing team	12 months

[39] *NHS England and NHS Improvement (2019) Transforming imaging services in England: A national strategy for imaging networks, https://improvement.nhs.uk/resources/transforming-imaging-services-in-england-a-national-strategy-for-imaging-networks/*

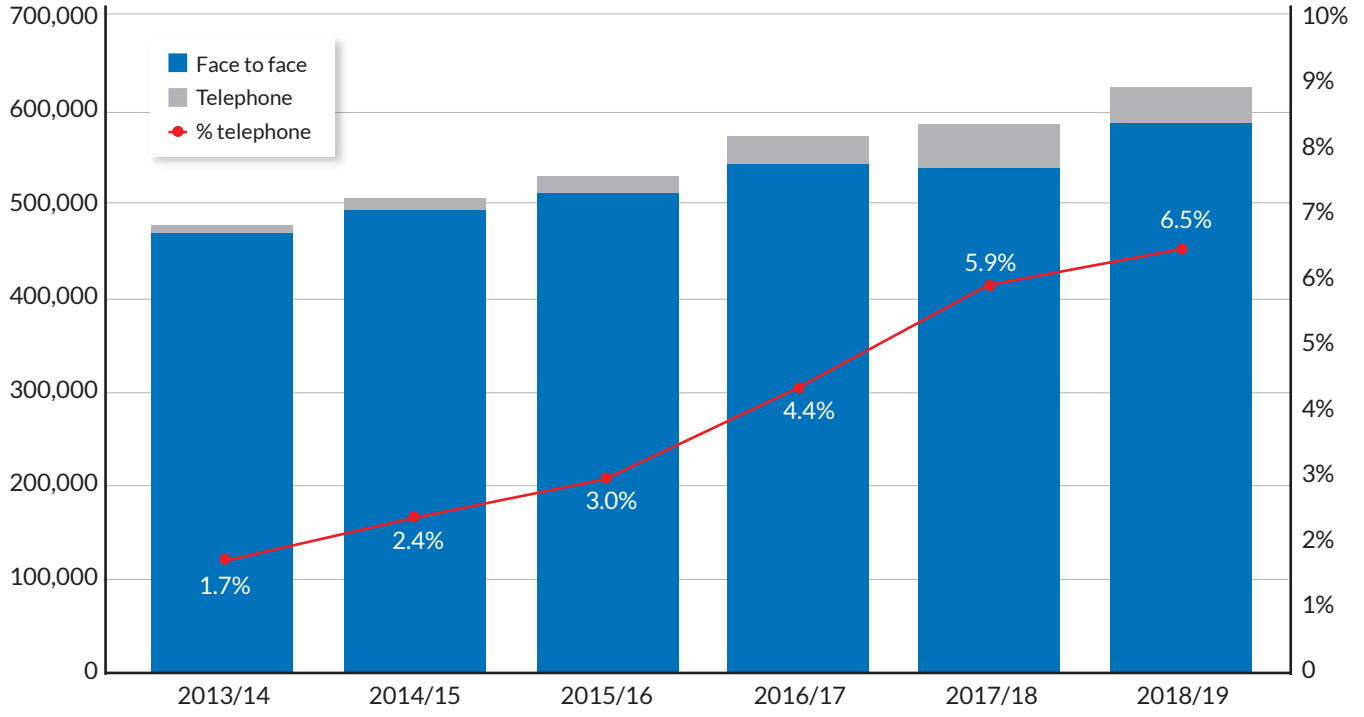
Innovations in endocrinology

Innovations are often linked to good use of technology, but during our deep-dive visits we also noted seemingly simple changes in practice that optimise patient care, many of which we cite in our case studies throughout this report. The most positive effects were seen in pre-testing/triage/referral, clinic management and patient follow-up.

Improving communications, saving time and reducing travel are all aspects of care where relatively small changes can make a significant difference. The presence of trained endocrine specialist nurses is another important factor that can optimise patient pathways at all stages. This is covered in the next section on the endocrine workforce (see page 55).

Since the patient numbers in endocrinology are increasing as recognition of the specialty grows, management of referrals, waiting lists and follow-up appointments is becoming increasingly challenging. Innovation in these areas is particularly welcome. Figure 10 below shows the growth in adult outpatient appointments for endocrinology over recent years (see also Figure 11) and the percentage of these appointments conducted by telephone.

Figure 10: Endocrinology outpatient attendance types



Source: HES OP data 2013-2019

The percentage of remote appointments is relatively low at 6.5%. We feel there is scope to increase this in line with General Medical Council Guidance[40] and to reduce the number of outpatient attendances overall by means of:

- increasing the number of blood/urine tests conducted prior to first outpatient appointment to enable more patients to be pre-investigated and triaged appropriately thereby reducing the number of investigative outpatient appointments and increasing rate of discharge at first appointment;
- increasing the number of follow-up appointments that can be conducted remotely in line with the drive towards 'digitally-enabled' outpatient care, as outlined in the NHS Long Term Plan.[41]

It is positive that remote appointments have already been implemented or increased in response to COVID-19.

Clinical/referral assessment services also support triage of outpatient referrals (based on our deep-dive visit findings, around 10% of referrals, if screened, do not need to attend an endocrine clinic).

[40] *General Medical Council (GMC) (no date), Prescribing and managing medicines and devices (online guidance), www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/prescribing-and-managing-medicines-and-devices/remote-prescribing-via-telephone-video-link-or-online*

[41] *NHS England (2019), The NHS Long Term Plan, www.longtermplan.nhs.uk/publication/nhs-long-term-plan/*

In addition, the NHS Advice and Guidance (A&G) service allows GPs to request diagnosis and management advice from a specialist team before or instead of referring patients to hospital. GPs can attach additional information to the A&G request. A&G is the most widely used platform and operates on the standard NHS e-Referral System (e-RS). NHS England and NHS Improvement and NHS Digital have produced a national e-RS A&G Toolkit to guide commissioners, clinicians and managers. Other commercial A&G platforms can be used instead of e-RS or to supplement e-RS A&G.

The e-RS A&G system offers the following benefits:

- full integration with the standard e-Referral System means minimal duplication of work for GPs;
- a way to keep records for future audit;
- no added upfront costs for the health system (in contrast to independently developed systems that may have one-off, maintenance or per-patient costs).

Endocrine nurses and doctors should have time allocated in their job plans to provide advice and guidance to GPs and patients.

Ratio of new to follow-up appointments

Using new-to-follow-up ratios as a performance indicator can be particularly challenging in endocrinology, where the nature of the conditions treated mean that in many instances long-term follow-up is a requirement of care. For example:

- An apparently successful thyroidectomy can lead to permanent hypoparathyroidism and lifelong dependency on high-dose supplements of vitamin D and calcium – without monitoring and long-term management this can lead to renal stones or even kidney failure.[42]
- Peer-reviewed research[43] shows that a significant proportion of patients (26%) with surgically treated non-functioning pituitary adenoma experience regrowth for the first time more than ten years after surgery and should attend regular scans for this reason.
- Patients who have been treated for thyroid cancer may require long-term follow-up, including TSH blood tests and in some cases a neck ultrasound. Their follow-up could be managed by way of an annual telephone consultation to discuss the results of these tests, all of which should be pre-booked.

We suggest that the Society for Endocrinology develops follow-up protocols for individual conditions where these are not currently formalised and that departments are benchmarked against these rather than being assessed against general new-to-follow-up ratios. Linked to this we fully support all efforts to increase the number of remote/virtual clinics for follow-up appointments in line with the NHS Long Term Plan.[44] Since specialist endocrine services tend to cover particularly wide areas and, taking into account the value of network models for the diagnosis and treatment of less common endocrine conditions, we would strongly encourage trusts to explore the options offered by increasing digitisation, as set out in the NHS Long Term Plan.[36]

While not strictly an innovation, it is important there is good communication with patients regarding support and management. In addition to a treatment plan, patients should be signposted to resources and patient groups to support ongoing management of their condition, irrespective of any formalised follow-up arrangements.

There are several charities across the UK that do great work in supporting patients with endocrine disorders. We have highlighted some below and encourage the sharing of these details with patients as appropriate:

The British Thyroid Foundation

www.btf-thyroid.org

The British Thyroid Foundation supports people with thyroid disorders and works with patients and medical professionals to provide information that is reliable and evidence-based.

The Pituitary Foundation

www.pituitary.org.uk

The Pituitary Foundation is a UK patient support organisation offering expert medical support and information on a range of diseases.

[42] *NICE is currently developing guidelines for thyroid cancer, which may include follow-up protocols.*

[43] *Reddy, R., Cudlip, S., Byrne, J. et al. (2011), Can we ever stop imaging in surgically treated and radiotherapy-naïve patients with non-functioning pituitary adenoma? European Journal of Endocrinology, 165: 739–744, www.ncbi.nlm.nih.gov/pubmed/21900406*

[44] *NHS England (2019), The NHS Long Term Plan, https://www.longtermplan.nhs.uk/publication/nhs-long-term-plan/*

Butterfly Thyroid Cancer Trust

www.butterfly.org.uk

Butterfly Thyroid Cancer Trust is the first national supporter of patients with thyroid cancer.

Amend (Association for Multiple Endocrine Neoplastic Disorders)

www.amend.org.uk

The Association for Multiple Endocrine Neoplasia Disorders (AMEND) is a patient group set up in 2002 to support and inform anyone affected by or interested in multiple endocrine neoplasia disorders and their associated endocrine tumours.

Parathyroid UK

www.parathyroiduk.org

Parathyroid UK is a volunteer-run charity that represents and supports the community of people living with hypoparathyroidism and hyperparathyroidism.

Addison's Disease Self Help Group

www.addisonsdisease.org.uk

Addison's Disease Self Help Group is a charity that works to support people affected by adrenal insufficiency, steroid dependency and Addison's Disease in UK and Ireland.

Diabetes UK

www.diabetes.org.uk

Diabetes UK helps fund research and provide information for people with diabetes.

CASE STUDY

Virtual clinics for results and care plans

Luton and Dunstable Hospitals NHS Trust

Face-to-face appointments are an inconvenience for many patients as they necessitate travel, costs and in many cases time off work. Virtual clinics are ideally suited to follow-up appointments with stable patients to relay blood test results or titrate medications. Virtual clinics offer increased convenience for patients, an efficient service for the department, and a decrease in non-attendance.

Nurse-led telephone clinic

In response to a long waiting list Luton and Dunstable Hospitals NHS Trust set up a nurse-led telephone clinic run by an endocrine specialist nurse. Following an initial treatment at a face-to-face appointment, dose titration for stable pituitary patients was conducted virtually. This avoided patient attendance, within safety parameters, for a maximum of 12 months. New appointments are still conducted in person to ensure a full assessment, a discussion of treatment options, and importantly forming a relationship of trust between the clinician and the patient.

Results

- The telephone clinic proved efficient and provided a safety net for abnormal blood results. Dose adjustments were made as needed and the format of further follow-up was decided on a case-by-case basis.
- The increased convenience for patients reduced rates of non-attendance (DNA).

To note

- The telephone service did not work well for non-English speaking patients as three-way translation proved difficult.
- The trust is exploring the best format for gaining anonymous feedback following telephone consultation.

CASE STUDY

Innovations in endocrine management

Guy's and St Thomas' NHS Foundation Trust

In 2017 Guy's and St Thomas' NHS Foundation Trust implemented a five-year strategy for their endocrine services. The strategy includes ambitious targets to reduce waiting times, prioritise urgent appointments, establish clear patient pathways supported by MDT working and a focus on structured follow-up (including nurse-led and virtual appointments).

Follow-up using virtual clinics

Virtual clinics have been adopted where a text service is used to schedule the time a patient receives their clinic phone call. Routine follow-up is conducted in virtual clinics that are nurse-led, enabling consultants to review more complex patients. Any further treatment required is noted after the virtual clinic and a letter is sent to the patient outlining their care plan.

Results

- Non-attendance (DNA) rates for clinics have reduced.
- Patient are seen promptly while avoiding the cost and time associated with attending a clinic in person.
- Patients have appreciated the written care plan outlining their care.

To note

- South London has launched an electronic health record system to ensure notes can be shared between trusts and GPs (local care record). Choose and Book Advice and Guidance and Consultant Connect complement this and allow primary care to contact specialists easily for advice. This was particularly valuable during the first wave of COVID-19. Pre-visit results (including medications and co-morbidities) are visible for patients seen in primary across Lambeth, Southwark and Lewisham.
- A related and evolving practise of 'enhanced referral management' is evolving, whereby discussion with GPs can eliminate the need to for a face-to-face appointment in secondary care for some patients and those clinic appointments for patients with urgent and/or complex requirements can be enhanced with multidisciplinary input, one-stop imaging and testing.
- Integrated software and communications systems have been vital to the success of these projects.

CASE STUDY

Telephone advice for primary care and patients

West Hertfordshire Hospitals Trust

Patients at West Hertfordshire were waiting several months to see a consultant for medication dose changes due to limited clinic capacity. With a rapidly growing service and increasing patient numbers, avoiding unnecessary referrals and allowing fast-tracking of patients to the right clinics would reduce pressure on the service. At the same time there was a need to offer rapid access to specialist nurses for patients requiring medication dose changes or urgent advice.

Advice Line

The now well-established telephone advice line for GPs to contact consultants was extended to offer direct telephone access for advice and management support from specialist nurses. This promotes timely investigations, triaging and fast-tracking of patients to the right clinics, while avoiding unnecessary referrals. In addition, patients are given contact details for the specialist nurse service when they attend clinics enabling a patient-centred service.

Results

- The new to follow-up ratio is better controlled, improving outpatient capacity and referral to treatment (RTT) times.
- Local GPs express a high level of satisfaction with the service and patient satisfaction has increased.
- Patients who need their medication dose changed no longer have to wait for a consultant appointment, which decreases anxiety and improves satisfaction.

To note

- The ability to seek advice without a face-to-face consultation (and to avoid unnecessary referrals) was particularly appreciated during the first wave of the COVID-19 pandemic, when hospital visits were being reduced.
- As referral numbers grow it is likely the service to patients will be further expanded in order to offer more virtual consultations.

CASE STUDY

GP–consultant liaison via e-consultation (Advice and Guidance)

Mid Yorkshire Hospitals NHS Trust

Inappropriate referrals by GPs can result in unnecessary patient journeys and unnecessary or duplicate testing, as well as placing undue strain on outpatient clinics. Conversely they may not always expedite an appropriately urgent referral.

Advice and Guidance for GPs

Since October 2016 the trust has introduced a system (using System 1 software) of e-consultations to support Advice and Guidance to GPs without the need for a letter or phone call. The query is sent to a designated endocrine or diabetes consultant with an agreed response time of 72 hours. The system allows a rapid review of the patient history and the response and recommendations are automatically recorded on the patient's electronic record. Most patients do not require a subsequent outpatient appointment and for those who do, the consultant can advise the GP on which tests to conduct prior to the consultation, ensuring patients can be discharged after a single clinic appointment where clinically appropriate.

Results

- From 1 April 2019 to 30 May 2020, 1,982 e-consultations took place. Average response time was 24 – 48 hours. Of the 1,982, 19% were converted to a face-to-face consultation.
- Reduced outpatient appointments have resulted in considerable savings to the CCG.
- Fewer unnecessary tests by GPs, more efficient clinics and an improved referral to treatment pathway.

To note

- Time to answer GP queries is allocated within consultants' job plans.
- Administrative support is provided by endocrine and diabetes secretaries.
- This is a flexible service and can be provided by consultants working remotely from hospital.

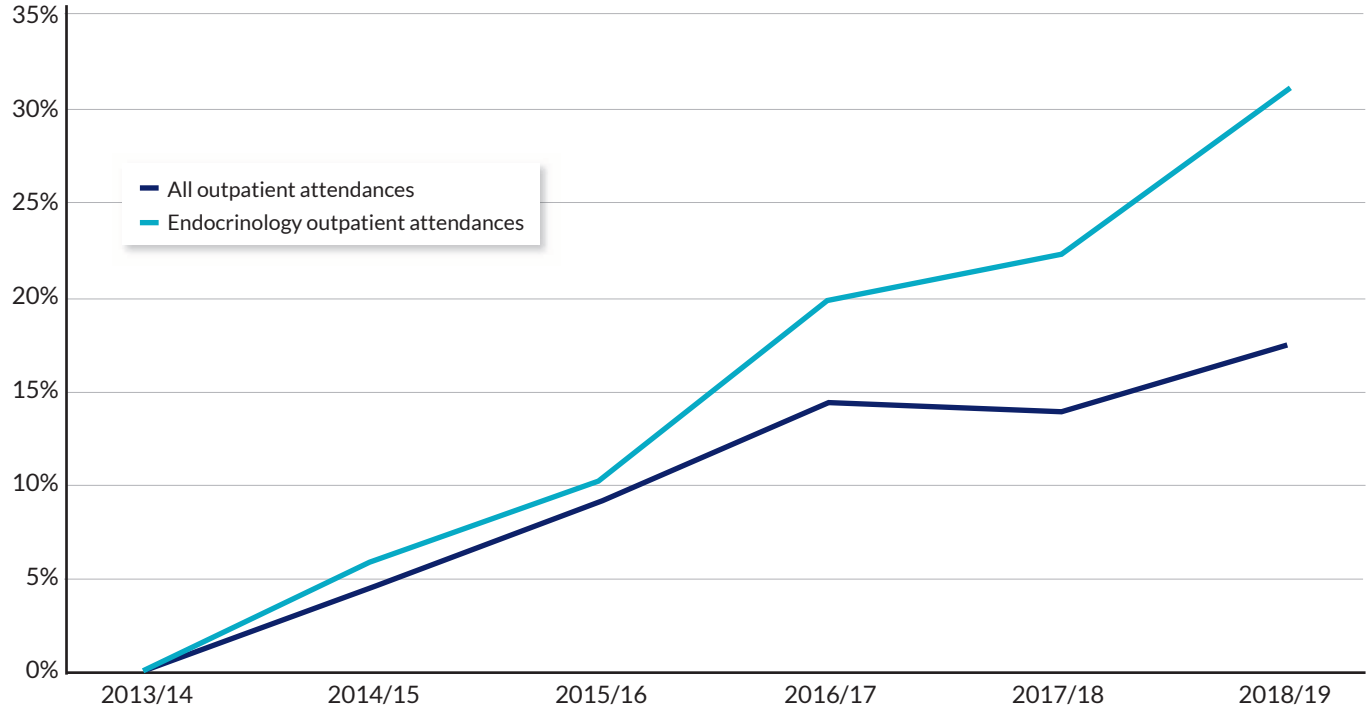
Recommendations

Recommendation	Actions	Owners	Timescale
9. Review appropriate triage and pre-investigation for outpatient referrals to improve patient flow, address capacity challenges and enable innovative practice.	**a** Trusts to review current protocols around pre-investigation diagnostic blood/urine tests prior to first outpatient appointment, to enable between 30-50% of patients to be pre-investigated and triaged.	Trusts	6 months
	b Trusts, with input from the Society for Endocrinology, to develop protocols for the implementation of clinical/referral assessment services to support appropriate triage of outpatient referrals and increase the likelihood of discharge at first appointment.	Trusts, Society for Endocrinology	12 months
10. Review management of follow-up appointments.	**a** Society for Endocrinology to develop follow-up protocols to ensure that endocrinology departments can benchmark performance against approved pathways for each endocrine condition.	Society for Endocrinology	12 months
	b GIRFT to work with the National Outpatient Transformation Programme to look at increasing availability of remote appointments/virtual clinics, especially for follow-ups.	GIRFT, NOTP	6 months
	c Trusts to explore options to advance to a core level of digitisation by 2024, as set out in the NHS Long Term Plan.	Trusts	12 months
	d GIRFT to work with the NHS pricing team and the National Outpatient Transformation Programme to review current pricing arrangements and incentives for video versus telephone appointments.	GIRFT, NHS pricing team, NOTP	6 months

Workforce

Endocrinology activity is growing and this inevitably puts a strain on the workforce. Figure 11 below shows that adult outpatient attendances have increased by 31% over the last five years, almost double the rate of overall NHS outpatient attendances.

Figure 11: Cumulative growth in Endocrinology outpatients 2013/14 to 2018/19



Source: HES OP data 2013-2019

Our questionnaire revealed that 66% of departments considered themselves to have a capacity problem. The most recent endocrinology workforce survey carried out by the Society for Endocrinology told a similar story and highlighted difficulties in recruiting consultants compared to other specialties of similar size.[45]

However, the biggest challenges we observed on our deep-dive visits appear to be in providing clerical and administrative resources to provide support for clinics in the face of growing outpatient numbers and, crucially, in providing suitable numbers of endocrine nurses to provide expert clinical care and leadership.

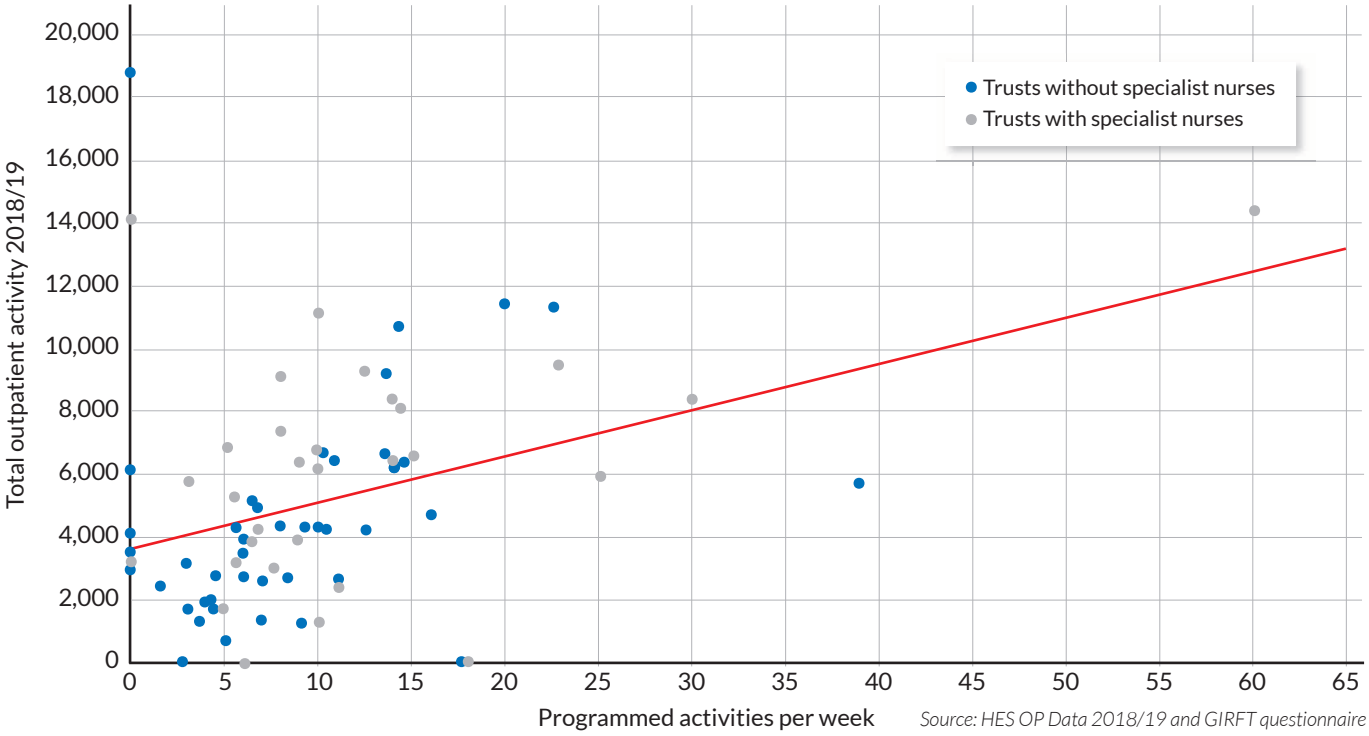
Specialist nurses

We have already mentioned the value of endocrine specialist nurses – they invariably enhance and streamline services. We heard on our deep-dive visits that some trusts found the addition of specialist nurses to their team to improve overall perioperative care. Their leadership and professional expertise is also extremely helpful in running clinics, whether for diagnostic tests/triage or follow-up over time (the trusts with the most efficient clinics in terms of pre-testing/screening referrals and list management tend to employ specialist nurses).

Figure 12 below shows the variation in activity for non-specialist endocrine departments and also shows how many are currently without specialist nurses.

[45] *2018 endocrinology workforce survey, as reported in the Agenda and Papers from Society for Endocrinology (10 June 2019)*

Figure 12: Number of consultant programmed activities per week and total outpatient activity for non-specialist trusts with and without specialist nurses



Source: HES OP Data 2018/19 and GIRFT questionnaire

Within a network or hub-and-spoke service model specialist nurses who travel between locations can offer an invaluable service to patients who require follow-up and monitoring by delivering these services in convenient locations. In some instances specialist nurses act as named contacts for patients post-operatively and during long-term follow-up, providing leadership for conditions such as Addison's or Graves' disease, where lack of training and ongoing support for patients can lead to complications, including a potentially fatal adrenal crisis.

> *Specialist nurses can help fill a gap in conducting follow-up for patients in long-term follow-up in their own clinic and so free up time in the medical clinic for new patients and those who have recently commenced treatment.*
>
> **The Pituitary Foundation**

After our deep-dive visits, we made recommendations to 96 out of 126 of departments (72.6%) that they appoint endocrine specialist nurses or expand their current nurse specialist team.[46] In order to maintain an optimal level of specialist nursing staff it is important that more nurses are encouraged to take up the Society for Endocrinology training courses.

Administrative support

In order to ensure smooth and efficient running of the clinics and follow-up and avoid unnecessary delays we would recommend one clerical support person be employed for every four clinics to ensure bookings are made in a timely manner and results and patient letters are sent out promptly. Voice-recognition software means consultants can dictate the body of these letters during appointments. A member of the administrative team who is familiar with the caseload can be expected to transcribe these letters by the end of clinic, for the consultant to sign.

[46] *There are now 125 departments, as two have merged since we began our deep-dive visits.*

Surgical training

In 2003, BAETS published guidance[47] for training in endocrine surgery. This has formed the basis of guidance from the General Surgery Specialist Advisory Committee. More recently, Europe-wide guidelines[48] on training in endocrine surgery have also been published. Following our discussions on deep-dive visits, we believe the Joint Committee on Surgical Training (JCST) should recommend these guidelines to the respective Specialty Advisory Committees (SACs) for General Surgery, ENT and Urology. Training across specialties should be aligned to ensure variation in skill and knowledge of endocrine surgery in training is addressed. If modules for thyroid, parathyroid and adrenal surgery are developed across these specialties it would be possible for these modules to be offered as part of post-CCT training as well. Such training should be part of discussions around supporting professional activity and continuing professional development. As such they should form part of the surgeon's job plan and be subject to audit.

CASE STUDY

Adrenal incidentaloma one-stop nurse-led clinic

Cambridge University Hospitals NHS Trust

In the past all adrenal incidentaloma (AI) referrals at CUH were reviewed at a standard endocrine clinic. Since in many cases these patients require no further treatment, this resulted in unnecessary outpatient appointments that cause patients needless journeys and delay their discharge.

Nurse-led clinic

Over the last 12 months 120 patients have been reviewed through the new AI nurse-led clinic. New referrals are discussed at a weekly adrenal radiology meeting, where imaging is reviewed. If the AI is less than 4cm maximum diameter, its appearance is in keeping with a benign adrenal adenoma and there are no red flags in the clinical history, the patient is referred to the nurse-led AI clinic. The patient is sent an information sheet and attends an appointment at the endocrine day unit for blood tests. These results and the outcome of the radiology meeting are reviewed by the endocrine nurse specialist and endocrine consultant. If the findings indicate a non-functioning adrenal adenoma and there are no other concerns, the patient is formally discharged. Where results are less clear or indicate potential malignancy the patient is offered a clinic appointment for further assessment.

Results

- Since the scheme began 98 out of 120 patients (81%) have been discharged without needing to attend a formal outpatient clinic appointment with an endocrinologist.
- The trust has been able to build an adrenal incidentaloma dataset, which facilitates effective and timely clinical audit and identification of potential research questions.

To note

- The success of the service depends on the expertise of specialist nurses.
- A significant amount of administrative work is required to support the service but this could be streamlined in the future.

[47] *British Association of Endocrine Surgeons (BAETS) (2003), https://www.baets.org.uk/wp-content/uploads/BAETS-Guidelines-2003.pdf*

[48] *Gimm, O., Barczynski, M., Mihai, R. et al. (2019) Training in endocrine surgery. Langenbeck's Archives of Surgery, 404: 929–944, https://link.springer.com/article/10.1007/s00423-019-01828-4*

CASE STUDY

Endocrine specialist nurse team

Sheffield Teaching Hospitals NHS foundation Trust

Over the last five years the number of endocrine specialist nurses at Sheffield has increased and included nurse prescribers to improve patient care and support patients and the endocrine team at every stage of the patient pathway.

Endocrine Investigation Unit

The four endocrine specialist nurses are based in the Endocrine Investigation Unit, where they perform pre-clinic and other dynamic testing as needed for all endocrine conditions. They also perform testing protocols for specific conditions, provide patient education and conduct telephone and face-to-face clinics for follow-up for ongoing treatment and post-operative care.

Results

- The endocrine specialist nurses see over 4,000 patients per year, freeing up time for consultants to see other patients with more complex needs.
- Nurse-led clinics for post-operative care reduce readmissions.
- Including nurse-prescribing has increased the nursing team's independence and efficiency.
- The team provides detailed care plans at discharge and as they spend more time with patients, are well placed to deliver education and support.
- As a point of contact for patients they help build continuity and support into the patient pathway.
- Both patient and staff satisfaction rates are extremely high.

To note

- The nurse specialists work closely and directly with consultants in key related specialties to enhance patient flow and care. This enhances seamless management between surgical and medical aspects and ensures a fully aligned service.
- On the basis of increased activity of the nurse specialist team, and on future capacity planning and patient feedback, a successful business case has recently been made to have the endocrine unit significantly expanded and refurbished.
- There is also open access Monday–Friday in the Endocrine Investigation Unit so patients can be seen on the day they enquire or can simply turn up.

> *The Endocrine Nurse Specialists working on the Endocrine Investigation Unit are essential. We couldn't deliver the service without them.*
>
> **Professor John Newell-Price, Endocrinology Consultant**

CASE STUDY

Endocrine specialist nurse-led thyroid clinic

West Hertfordshire Hospitals Trust

Increasing referrals/waiting times and growing consultant workload at West Hertfordshire led to the establishment of weekly nurse-led thyroid clinics in 2015. There remained a need to further reduce consultant-led outpatient activity, increase the patient–nurse link to improve disease management and increase patient satisfaction.

Nurse-led telephone clinic

In addition to the face-to-face clinics, the service set up a nurse-led telephone clinic that serves over 1,000 patients in a catchment area over three sites. Using the Infoflex system allows patient–nurse interaction to be documented and creates a communication channel between the specialist nurse team and primary care so care can be jointly managed with minimum disruption and waiting times.

Results

- Reduced consultant workload and reduced waiting times for outpatient clinics.
- Timely access to advice and support has improved post-treatment management of patients having radioactive iodine.
- Having a single point of contact has improved continuity of care and also compliance for patients.
- Outpatient department patient satisfaction levels are 100%.

To note

- The trust holds 204 nurse-led clinic slots a year. In 2019 156 were utilised, showing a growing demand for the service.
- Both the specialist nurses are also nurse prescribers.

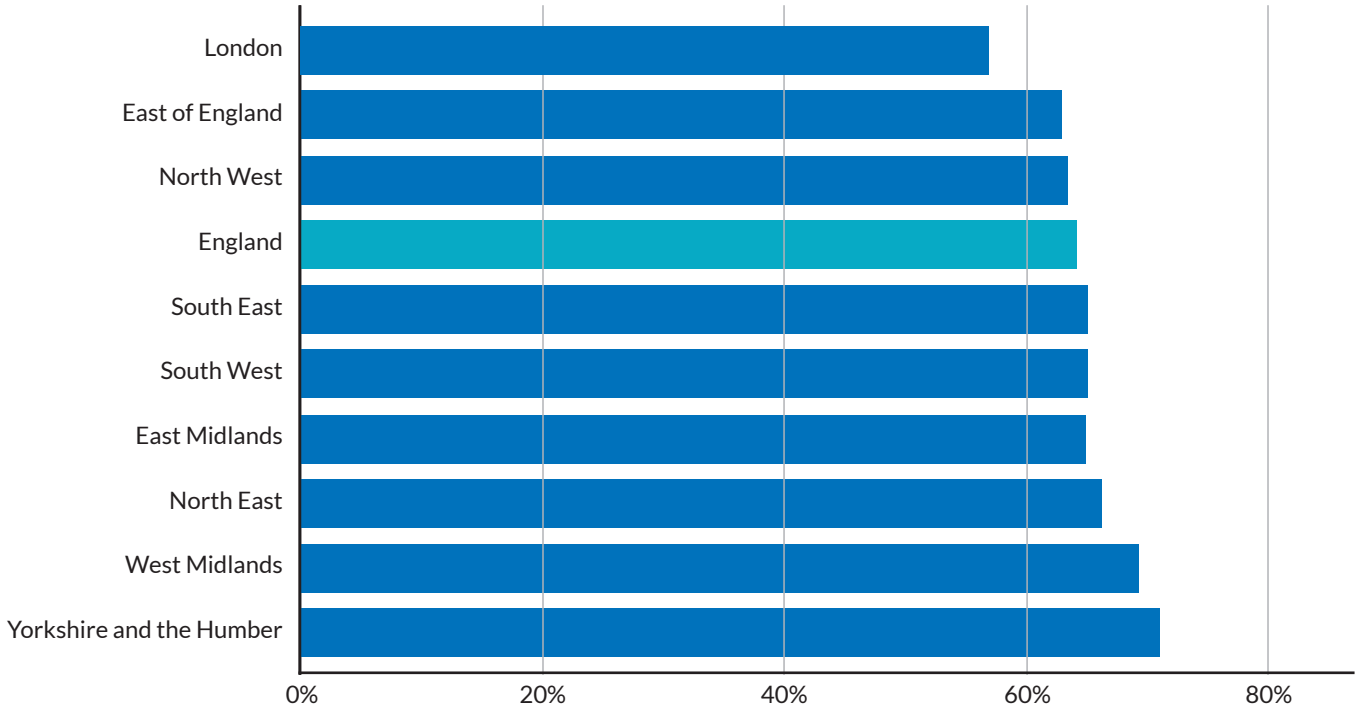
Recommendations

Recommendation	Actions	Owners	Timescale
11. Ensure all surgeons and wider team members involved in endocrine activity have access to the latest information and training to maintain their competence.	**a** GIRFT and Joint Committee on Surgical Training (working with the specialty and subspecialty Specialist Advisory Committees) to jointly produce a cross-specialty endocrine surgery module for pre- or post-certificate training.	GIRFT, JCST, SAC	12 months
	b Trusts should endeavour to facilitate and support endocrinology-specific training for the wider endocrinology team, including Society for Endocrinology training for nurses.	Trusts	12 months
12. Ensure the endocrinology department is fully optimised to release clinicians' time to care in line with associated NHS People Plan programmes.	**a** To enable better workforce planning and support service delivery, trusts should review the resourcing of their endocrinology MDTs and relevant surgical services considering in particular: i. Employing at least one but ideally two specialist nurses (dependent on department workload/ demand) to carry out pre-investigation assessments for outpatients, lead clinics and support pre/post-operative care. The specialist nurse support for the surgical service may be the same or separate from that for the endocrinology service. Trusts would need to make a business case to ascertain the value of this action. ii. Increasing administrative and clerical resource to provide support for clinics.	Trusts	For immediate discussion
	b GIRFT to work with NHS England and Improvement People Directorate to action specialist nursing workforce needs in endocrinology and encourage uptake of Society for Endocrinology training courses for specialist nurses.	GIRFT, NHS England, NHS Improvement People Directorate	12 months

Implementing Tier 3 obesity services

Obesity is a highly prevalent condition, present in 28.7% of adults in England. A further 35.6% are overweight.[49] Prevalence varies by region, as illustrated in Figure 13 below.

Figure 13: Regional prevalence (overweight or obese)



Source: NHS Digital (2019), Statistics on obesity, physical activity and diet, 2018

Complications of obesity include type 2 diabetes, heart disease, high blood pressure, stroke, fatty liver disease, an increased incidence of a number of cancers and an increased susceptibility to COVID-19 complications. According to Public Health England, the UK-wide NHS costs attributable to people being overweight or obese are projected to be £9.7 billion by 2050.[50] By age 10/11 around 30% of children are overweight or obese, which gives some indication of the future scale of the problem.[51]

Obesity falls within the specialty of endocrinology and diabetes and is a known risk factor for type 2 diabetes. Bariatric medicine, which deals with the treatment and prevention of obesity, is also a developing specialty within the purview of endocrinology.

In England, NICE has published guidance on the provision of specialist (non-surgical) weight management services[52] and this has been reviewed by Welbourn, Hopkins, Dixon et al.[53] who have produced a model for organising multidisciplinary team (MDT) clinics that could be developed in every healthcare system. Figure 14 below shows the framework they propose.

[49] *NHS Digital (2019), Health Survey for England 2018, https://digital.nhs.uk/data-and-information/publications/statistical/health-survey-for-england/*

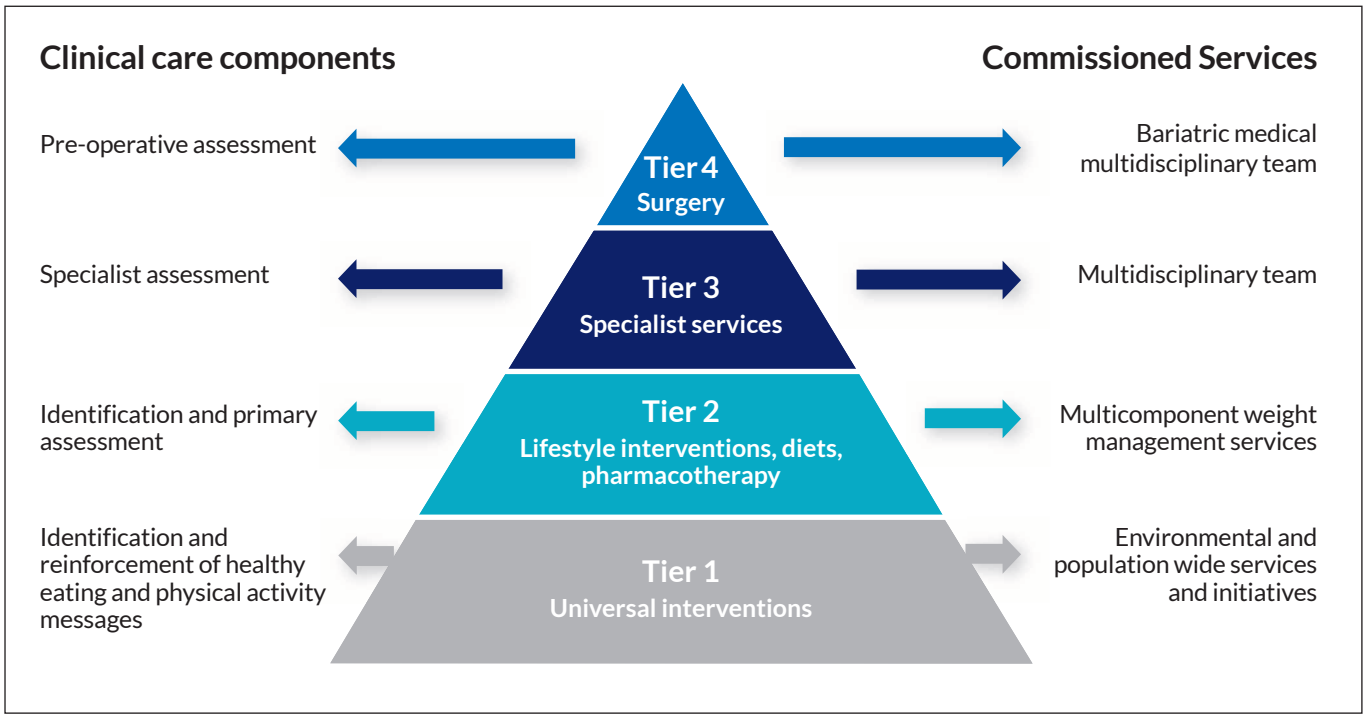
[50] *Public Health England (2017), Health matters: Obesity and the food environment, https://www.gov.uk/government/publications/health-matters-obesity-and-the-food-environment/health-matters-obesity-and-the-food-environment--2*

[51] *Professor Dame Sally Davies (2019), Time to solve childhood obesity: An independent report by the Chief Medical Officer, https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/837907/cmo-special-report-childhood-obesity-october-2019.pdf*

[52] *National Institute for Health and Care Excellence (NICE) (2014), Obesity: identification, assessment and management (CG189), https://www.nice.org.uk/guidance/cg189*

[53] *Welbourn, R., Hopkins, J., Dixon, J. B. et al. on behalf of the Guidance Development Group (2017) Commissioning guidance for weight assessment and management in adults and children with severe complex obesity. Obesity Reviews (World Obesity Foundation), DOI: 10.1111/obr.12601.*

Figure 14: Framework for obesity management in England

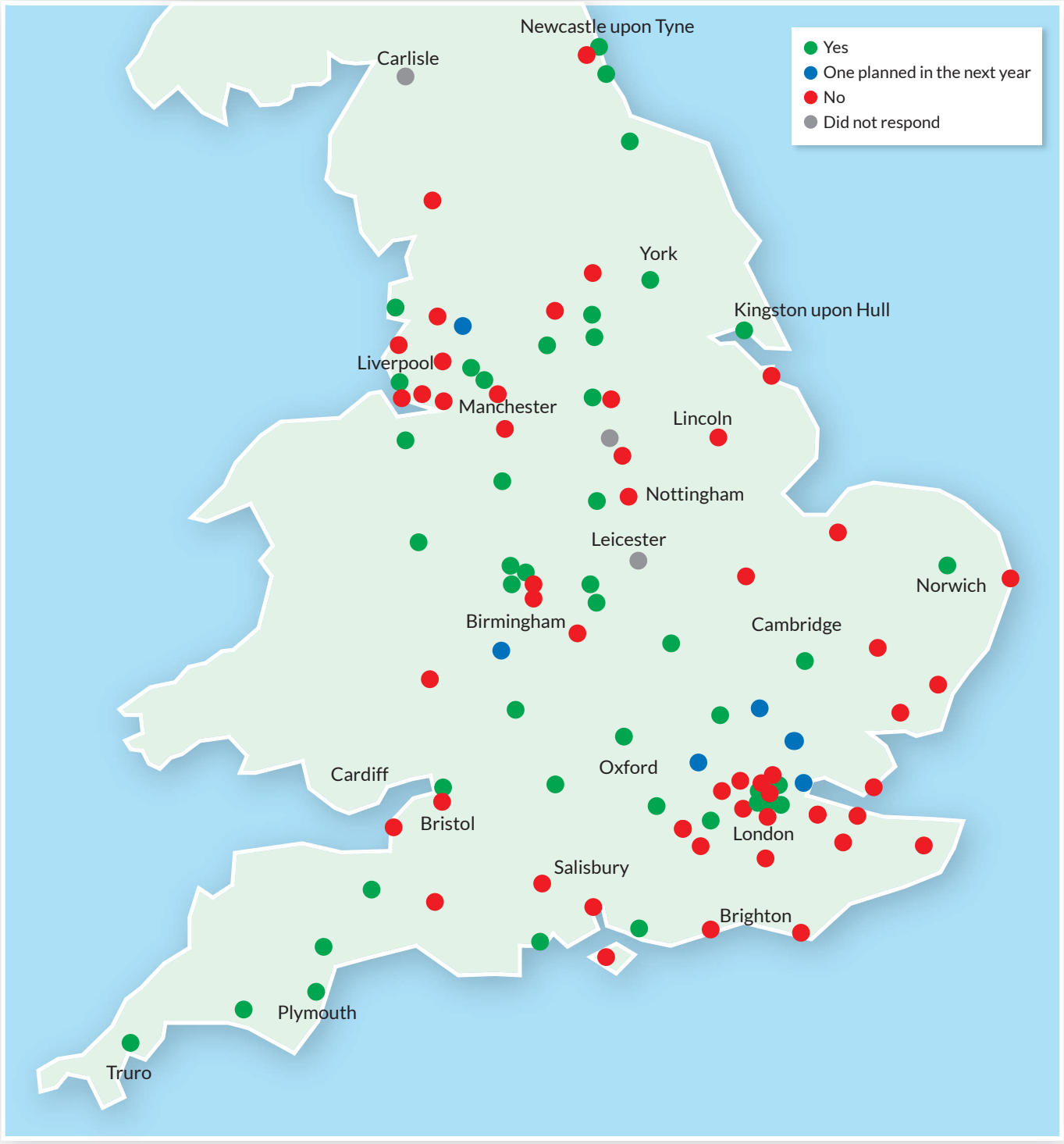


Source: Welbourn, Hopkins, Dixon et al

During our deep-dive visits, we ascertained that currently only around 44% of trusts in England have obesity services at Tier 3 or above (noting, however, that the accuracy of self-assessment in this matter cannot be assured), despite a demonstrable need for nationwide services, with the result that the challenge of managing the epidemic of patients with severe and complex obesity disease in secondary care remains largely unmet, as highlighted in Figure 15 below.

While the focus has previously been on prevention, there is a growing acknowledgment of the need to offer help and treatment to people living with obesity and related conditions. While moderately obese people or those without complex health needs may be suitable for Tier 1 (community) and Tier 2 (GP-focused) advice and treatment, those with more severe and/or complex needs should be referred to a Tier 3 service usually based in a hospital where care is delivered by an MDT that includes, as a minimum, an endocrinologist/diabetologist, a specialist nurse, a dietician, a psychologist and physiotherapist/exercise adviser. Given the widespread nature of obesity in England, there should be widespread access to Tier 3 services. In some cases, patients will need to be referred to Tier 4 (specialist care) for bariatric surgery under a surgical MDT or a hub and spoke team. There are currently 46 units in England offering Tier 4 (bariatric surgery) services. While we note the importance of bariatric surgery as part of an obesity service, we do not have the data necessary to include it within the scope of these recommendations at present.

Figure 15: Multidisciplinary obesity services in England by provider



Source: GIRFT questionnaire

We would suggest that every endocrinology unit without a dedicated obesity lead in the team should appoint one and that this role feed into an existing or nascent MDT to manage obesity services at Tier 3. This could be coordinated through Integrated Care Systems. We also suggest that urgent attention be given to implementing Tier 3 obesity services where these are currently lacking. For both of these steps we would advise that trusts conduct their own financial impact assessments. Data analysis should be undertaken to measure the cost- effectiveness for Tier 3 services. By implementing a national database, services could be commissioned to defined criteria and their effectiveness could be audited.

CASE STUDY

Tier 3 obesity services

Portsmouth Hospitals NHS Trust

The growing national problem of obesity, with all the attendant health implications, is compounded by inadequate and patchy provision of easily accessible services at Tier 3. A multidisciplinary approach to weight management over a set period time can allow patients with clinicians to optimise their care, and where applicable escalate to a Tier 4 service for surgery.

Integrated Complex Obesity Service

Portsmouth Clinical Commissioning Group (CCG) has established the Integrated Complex Obesity Service (ICOS), a Tier 3 service offering an MDT approach to weight management. The team based at ICOS includes an endocrine physician, specialist dietician and specialist eating behavioural therapist as well as MDT support and physiotherapist-led exercise sessions. ICOS runs a six-month programme, taking a holistic approach to weight loss that can respond to the needs of individual patients such as offering additional sessions.

Results

- The CCG has recently confirmed support of the programme for a further five years.
- The ICOS team won a Pride of Portsmouth award after being nominated by an individual who had been through the service.

To note

- Including an endocrinologist allows for optimisation of weight loss interventions and the management of related co-morbidities, which in turn reduces waiting times between completion of Tier 3 and potential Tier 4 intervention.
- The ICOS is held in a community site within Portsmouth to better meet the needs of those using the programme.
- The service has designed a single-page pro-forma for primary care to easily refer patients to the service.

CASE STUDY

Tier 4 obesity services

Portsmouth Hospitals NHS Trust

Where surgical intervention is required, lengthy waiting times and multiple hospital visits for Tier 4 services are common. Efficient diagnostic testing, along with MDT assessment, can ensure patients are ready, both physically and psychologically, for surgery.

One-stop Tier 4 obesity clinic

Portsmouth Hospitals NHS Trust has developed a one-stop Tier 4 clinic taking referrals from both local and national Tier 3 services to assess those requiring metabolic surgery. Alongside this is an MDT, which includes an endocrinologist, to assess patients' readiness and suitability for surgical intervention. As soon as the MDT has ensured all aspects of care are up to date, the patient can be listed for surgery.

Results:

- Prior to the COVID-19 pandemic, the waiting time for surgery following attendance at the Tier 4 clinic was approximately four months.
- The combined approach and collective expertise of the MDT means referrals are received from across the country.

Recommendations

Recommendation	Actions	Owners	Timescale
13. Improve access to weight assessment and management services for patients with complex obesity.	**a** Endocrinology units should appoint a dedicated obesity lead in their team (where they have not already).	Trusts	6 months
	b Trusts should work with integrated care systems to implement Tier 3 obesity services, with a specialist multidisciplinary team in place to assess and manage patients (where they have not already).	Trusts, ICSs	1 – 2 years
	These actions are also endorsed by the GIRFT clinical leads for diabetes.		

Improving data quality and data collection

Engagement with clinicians transforms data. Although there are some historical issues and anomalies within specific trusts that need to be addressed, there is also a clear and recognised need for, quite simply, improved communication and engagement between endocrinologists and those staff responsible for recording clinical activity accurately and against its correct specialty. In the current landscape, the work of endocrinologists is not being recorded accurately. For example, at least eight of the trusts we visited entered no outpatient activity despite seeing patients. This has implications for the specialty as a whole, as well as for commissioners of services and for patients, all of whom need accurate data in order to make informed choices. In general, the coding issues we found related to endocrinology rather than endocrine surgery, where the data appears to be more accurately attributed.

Assigning endocrine activity to the correct specialty

As is the case for all specialties, to ensure that endocrine activity can be identified easily, all clinical activity must be assigned to the correct 'Main Specialty' and 'Treatment Function' Codes. All consultants (in all specialties) are assigned a Main Specialty Code by their employing trust and this must reflect what is in their job plan. Endocrinologists may be registered under one of two Main Specialty Codes: '302' (endocrinology) or '300' (general medicine), as explained below.

An endocrinologist that provides only endocrine services and care should be assigned a Main Specialty Code of 302 (endocrinology). However, many endocrinologists, particularly in smaller hospitals, also provide some 'generalist' care as part of their job plan. Any consultant (in any specialty) who has a generalist component to their work i.e. provides ongoing care for unselected emergency referrals as part of their job plan, must be assigned Main Specialty Code 300 (general medicine), so these endocrinologists will be recorded under Main Specialty 300.

It is reasonable to assume that in specialist centres, fewer endocrinologists will have generalist duties and that there would be correspondingly less or no endocrine activity recorded under Main Specialty 300 (general medicine). However, this is not as evident in the data as might be expected. This may suggest that in some cases endocrinology consultants are not being assigned to the main specialty best aligned with their job plans and that trusts and consultants should review this together for the purpose of recording clinic activity data accurately.

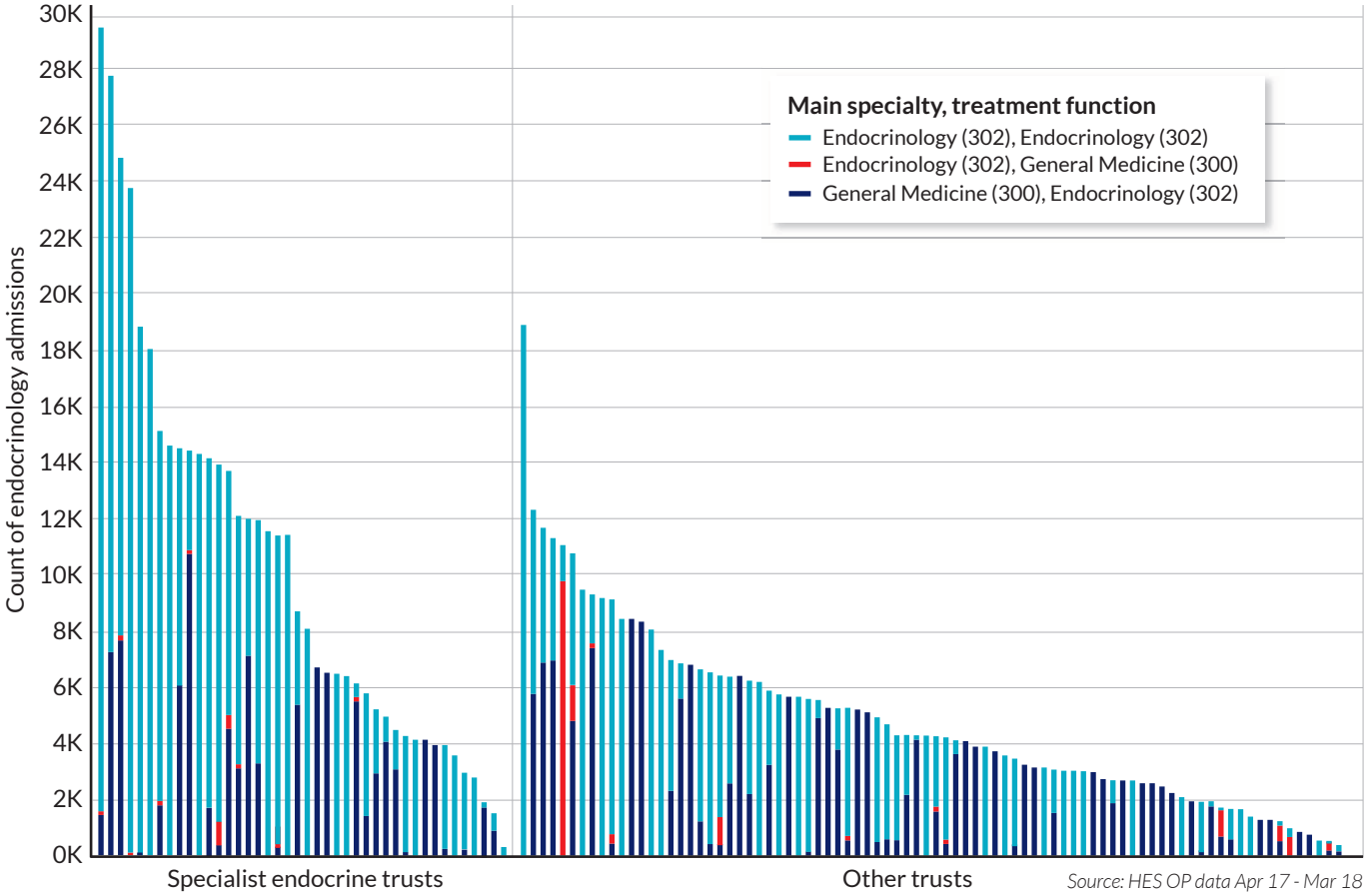
Despite this, endocrinology activity should still be identifiable using the 'Treatment Function Code' (TFC). This records the specialised service within which the patient is treated (as opposed to the consultant providing the care). All care provided within the endocrinology specialty should be recorded with TFC 302 (endocrinology), regardless of whether the endocrinologist providing the care has been assigned a Main Specialty Code of 302 or 300.

We would therefore expect to see two 'correct' combinations of Main Specialty and Treatment Function codes, these being

- Main Specialty 302 (endocrinology), Treatment Function Code 302 (endocrinology)
- Main Specialty 300 (general medicine), Treatment Function Code 302 (endocrinology)

In practice, outpatient coding was for the most part in line with this, as can be seen in Figure 16 below (although there are some anomalies and one trust recorded virtually all endocrinology activity, incorrectly, under Treatment Function Code 300).

Figure 16: Endocrinology outpatient appointments by main specialty and Treatment Function Codes

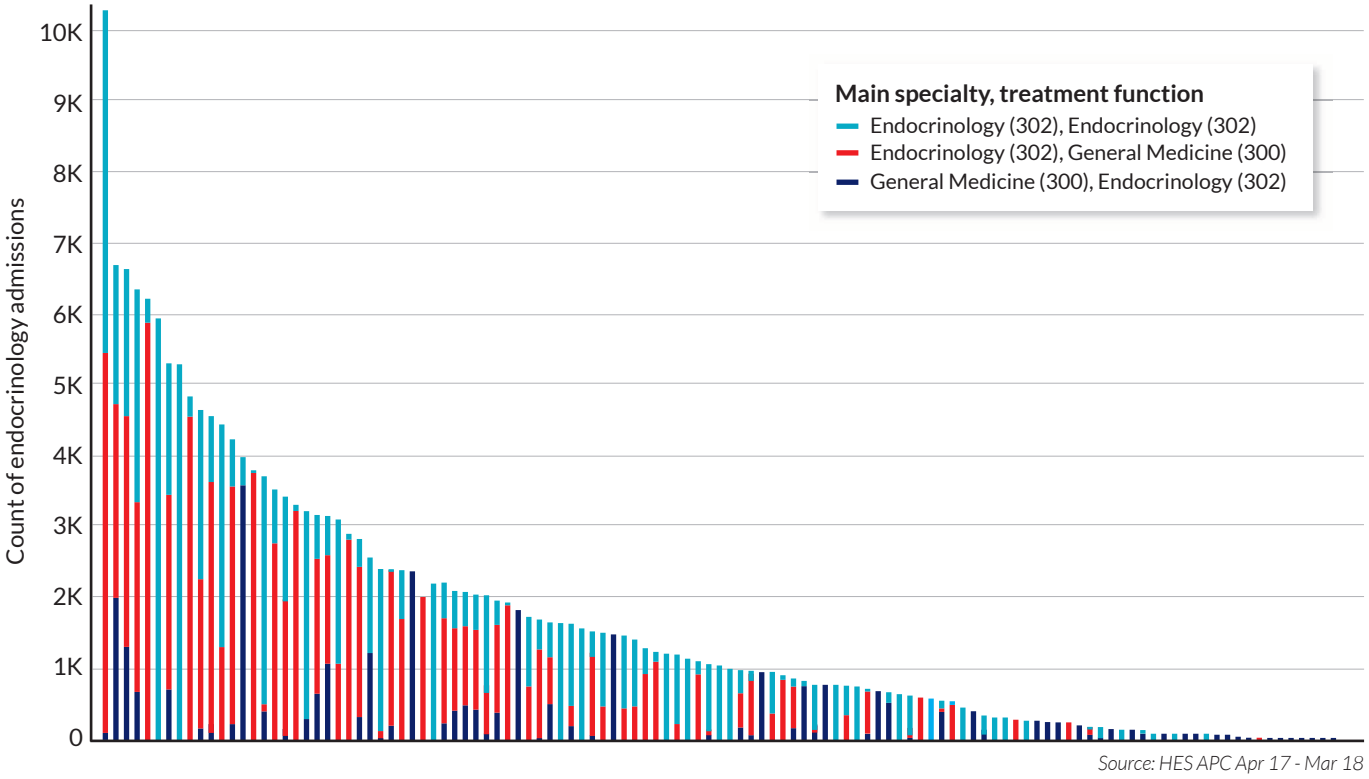


In the figure above it can be seen that few trusts are recording activity incorrectly. Incorrect coding in this instance is where an endocrinologist (specialist code 302) is treating patients under treatment function code general medicine 300, as highlighted in red on the chart.

The situation is significantly more variable for admitted patient care, with a considerable amount of activity recorded against Main Specialty 302 (endocrinology) with Treatment Function Code 300 (general medicine). This combination is not compatible since it would imply that an endocrinologist who does not have responsibility for the ongoing care of unselected emergency admissions is routinely providing care in the specialty of general medicine. We suspect that this coding combination means that the endocrinologists providing the care have not had their main specialty assignment aligned with their current job plans (to reflect that they have a generalist component to their job), but it could also relate to incorrect assignment of Treatment Function Codes (which we found to be the case in at least one trust). Clearly detailed discussions need to be held between clinicians and those apportioning their activity in every trust.

Figure 17 below highlights that coding of endocrinology-related admissions activity is unreliable, as explained in the previous paragraph (see the high proportion of red, indicating a combination of Main Specialty 302 and Treatment Function 300), and that this makes it difficult to use HES data to track activity levels and understand what is happening from a clinical perspective.

Figure 17: Endocrinology admissions by main specialty and Treatment Function Codes



Source: HES APC Apr 17 - Mar 18

We therefore recommend that endocrinology activity should be recorded in one of two ways, whichever most accurately reflects the job plan of the consultant who undertook the activity:

- Main Specialty 302, Treatment Function Code 302 or
- Main Specialty 300, Treatment Function Code 302.

Further anomalies

- One hospital saw 2000 endocrine outpatients per year but erroneously coded all endocrine cases as diabetes.
- A large teaching hospital also erroneously assigned no outpatient visits for endocrinology.
- In one hospital, neurosurgical procedures were recorded as hysterectomies.

Coding day cases

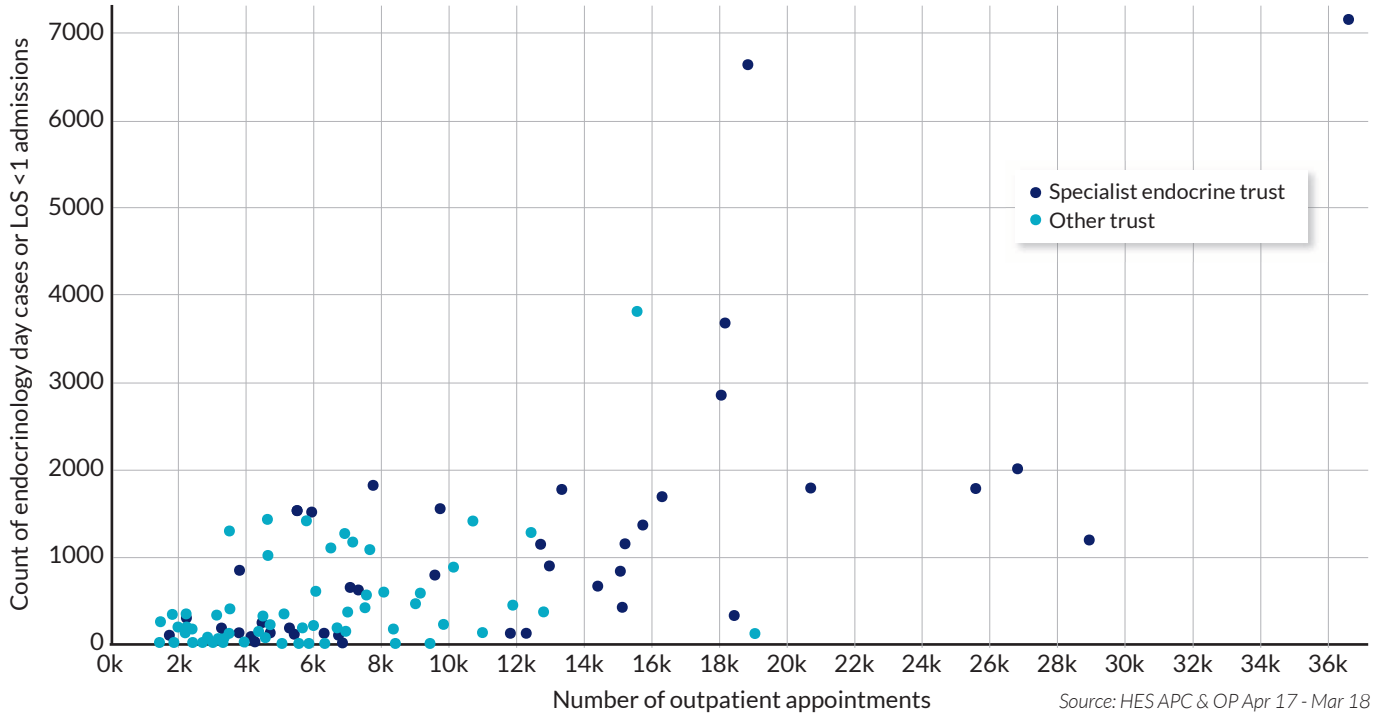
Day case procedures are being recorded inconsistently, so volumes are variable and do not reflect the true picture. Thus some hospitals are recording hundreds of day cases and others none. It is important both for the specialty and for the purposes of commissioning services that day cases are correctly recorded as such and are correctly attributed to endocrinology.

A day case is defined as:

A patient admitted electively during the course of a day (i.e. Not in an outpatient clinic) with the intention of receiving care who does not require the use of a Hospital Bed overnight and who returns home as scheduled. If this intention is not fulfilled and the patient stays overnight, such a patient should be counted as an ordinary admission.[54]

Figure 18 highlights inconsistency in either practice or recording of activity as day cases. We would expect to see a clear relationship between the number of endocrinology day cases and total number of endocrinology outpatients by trust. For example, we would expect to see more day cases at specialist trusts, and this appears to be the case. However, there is no clear relationship between the number of outpatient appointments and the number of day case admissions here. This suggests either that there is wide variation in clinical practice or that coding of day cases is inconsistent. We believe the latter to be the case.

Figure 18: Endocrinology day case/outpatient numbers



Source: HES APC & OP Apr 17 - Mar 18

There is currently no clear guidance on which endocrinology procedures (including diagnostic tests) can be conducted as day cases, as opposed to being carried out on an outpatient basis. Since day case activity attracts a higher tariff than an outpatient appointment it is important that hospitals record these correctly. For this reason we propose that a definitive list be produced. This list will also help define which day case procedures should be coded for endocrinology and not general medicine.

[54] *NHS Data Model and Dictionary Version 3, (2020) www.datadictionary.nhs.uk/data_dictionary/attributes/p/pati/patient_classification_de.asp?shownav=1*

Proposed day cases procedures

We would suggest that for endocrine diagnostic testing and surgical procedures the following be designated as day case activity:

- Thyrotrophin-releasing Hormone (TRH) test;
- insulin tolerance test for hypopituitarism;
- glucagon test for hypopituitarism;
- arginine infusion for growth hormone reserve;
- water deprivation test for diabetes insipidus;
- glucose tolerance test for acromegaly;
- octreotide suppression test for acromegaly;
- saline infusion for Conn's syndrome;
- acid load test for renal tubular acidosis.

This list is not exhaustive and it should not be assumed that everything not covered here can be treated as standard outpatient activity. There is further discussion to be had around procedures which currently require more time/resource than a standard outpatient appointment. We recommend that work begin on clarifying the current guidance around procedure type and coding and that pricing is reviewed and clarified accordingly.

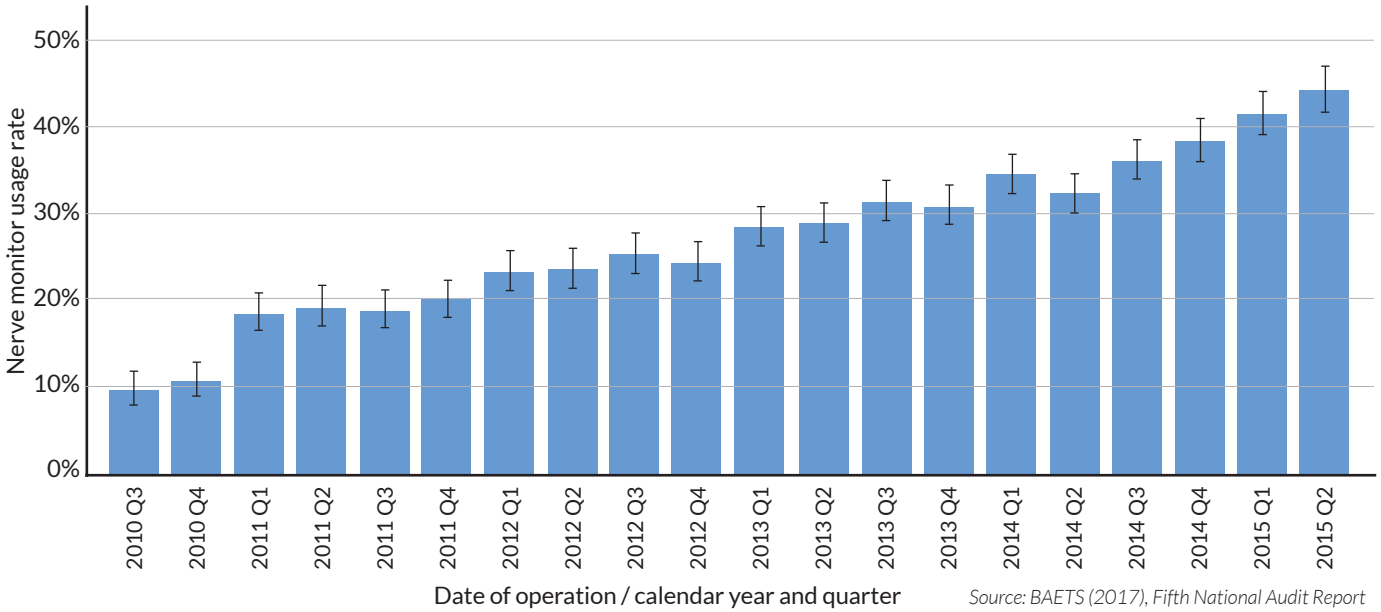
Recommendations

Recommendation	Actions	Owners	Timescale
14. Accurately assign main specialty and treatment function codes to ensure endocrinology activity is appropriately captured.	**a** Trusts to ensure all endocrinology activity is coded using treatment function code 302, and either main specialty code 300 (general medicine) or 302 (endocrinology), according to the job plan of the consultant who undertook the activity.	Trusts	12 months
15. Ensure there is clear and consistent delineation between outpatient and day case endocrine activity and that pricing arrangements reflect this.	**a** Society for Endocrinology, in collaboration with GIRFT, to produce clear guidelines around which endocrinology procedures should be conducted as day cases (using proposed list - see page 80).	Society for Endocrinology, GIRFT	6 months
	b GIRFT endocrinology team to feed into the GIRFT coding workstream with insight on procedures which require more time/resource than a standard outpatient appointment, but less than day case activity.	GIRFT	12 months
	c GIRFT to work with NHS England and NHS Improvement to review pricing arrangements for outpatient and day case procedures to standardise funding and incentivise best practice.	GIRFT, NHS England, NHS Improvement	12 months

Nerve monitoring and haemostatic devices for use in surgery

Nerve monitoring refers to the use of a variety of devices to help confirm the identification and preservation of the recurrent laryngeal nerve during thyroid surgery. Although the use of these devices has not been proven to reduce the incidence of vocal palsy, there has been a remarkable increase in their usage, from under 10% in Q3 2010 to over 40% in Q2 2015, as shown in Figure 19 below. There is a slightly higher rate of nerve monitoring in cancer versus non-cancer cases (33.2% versus 26.8%), and in re-operative versus first-time cases (with little difference between cases ipsilateral or contralateral to the previous surgery).[55]

Figure 19: Thyroid surgery: Nerve monitoring usage rates over time (n=28,091)



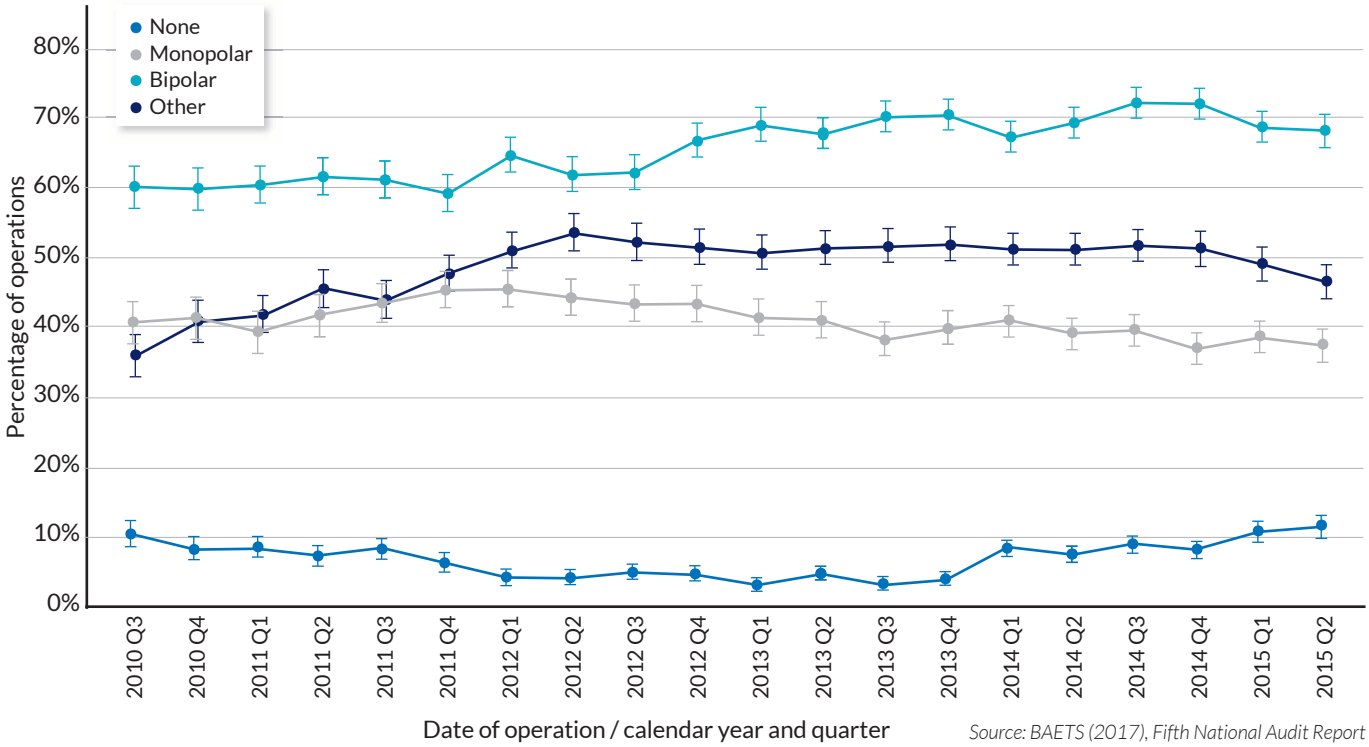
Source: BAETS (2017), Fifth National Audit Report

BAETS notes that usage appears to depend purely on individual surgeon preference, with many new members recording high usage rates for these devices while a significant proportion of surgeons report never using them. It should be noted, however, that use of nerve monitoring has become standard of care in some countries such as Germany. Surgeons and trusts should carefully consider the utility of these devices before making the considerable investment required. It may also be advisable to compare prices paid across trusts for the various models.

Similarly, use of advanced cutting and tissue sealing devices for haemostasis has also risen over recent years, as shown in Figure 20 below. Over the period from Q3 2010 to Q3 2015, rates of use for Harmonic scalpel and LigaSure models for total thyroidectomy were 32% and 25% respectively. In this case too we would advise trusts to carefully consider the value of these devices, which is most suitable for the trust's requirements and to compare prices with those paid by other trusts.

[55] *Data in text and figures sourced, BAETS Fifth National Audit Report 2017. Available from www.baets.org.uk*

Figure 20: Thyroid surgery: energy source (n=30,557)



Source: BAETS (2017), Fifth National Audit Report

General procurement issues

In 2016 NHS Improvement mandated all trusts to submit their monthly purchase order data to a central database – the Purchase Price Index & Benchmarking data tool (PPIB). This is the first time a single national dataset of procurement information has been established for the NHS. For the last 18 months the GIRFT programme has been analysing this data to better understand the variation in products and brands used and prices paid across NHS trusts. This analysis has been a feature of previous GIRFT reports with examples of extreme variation in the number of brands used by clinicians.

What has become clear in recent months is that this variation is often down to clinical choice, and there has been a growing list of examples where the evidence-base to support these decisions has been weak and in some cases patient safety has been compromised. Unsurprisingly this has received media attention and there have been debates on the House of Commons and House of Lords to debate what could be done to improve the situation.

The extreme variation not only compromises patient safety, but it also adds significant costs to the NHS Supply Chain, as every brand used requires inventories and NHS purchasing leverage is compromised. Addressing variation therefore not only improves safety and efficacy, but provides the opportunity to secure better deals and improved value for money for trusts.

To help, GIRFT has established a programme to root out unwarranted variation, improve the evidence-base to enable better decision-making, accelerate adoption of new proven technologies, and improve overall value for money by reducing supply chain costs. The GIRFT Clinical Technology Optimisation programme has been working with GIRFT Clinical Leads to examine the data and evidence that support products and, in some cases, national Clinical Technology Advisory Panels (CTAPs) have been established with leading clinicians from the specialty to address safety, efficacy, innovation and value – with the objective of providing better information to clinicians and procurement professionals across the NHS.

In addition to this, NHS England and NHS Improvement recently launched a new NHS Spend Comparison Service to replace the PPIB dataset.[56] The new service allows trusts to compare the products they use and prices they pay with other trusts across the NHS. The service is primarily targeted to NHS procurement staff, but GIRFT is working to tailor the data for medical directors and NHS clinicians, and place it alongside clinical outcome and HES data, so they can better understand the consequences of the decisions they make.

[56] *https://digital.nhs.uk/data-and-information/data-collections-and-data-sets/data-collections/spend-comparison-service*

GIRFT has also been working with the new NHS operating model for NHS procurement, including the new Category Towers (CTs), to develop plans for helping trusts and clinicians to address variation and improve value for money.

Reducing unwarranted variation and improving value for money

Over the coming months, and using the new Spend Comparison Service data, the GIRFT procurement team will be working with GIRFT clinical leads and trusts to understand more about the variation in procurement costs across all clinical specialties. The GIRFT programme recognises that there are often sound clinical reasons behind the device and treatment method choice, and that patient quality outcomes, product evidence and product innovation are key considerations alongside supply chain efficiency and best value. As part of this review, the GIRFT team will provide trusts with curated data and will be asking medical and procurement teams to validate and provide evidence for choices made.

The Department of Health and Social Care is expecting the new procurement Category Towers to help trusts reduce the level of variation in procurement by flexing the buying power of the NHS. Trusts are encouraged to work with the new Category Towers to support the rationalisation and standardisation of procurement.

Recommendations

Recommendation	Actions	Owners	Timescale
16. Enable improved procurement of devices and consumables through cost and pricing transparency, aggregation and consolidation, and by sharing best practice.	**a** Use sources of procurement data, such as the NHS Spend Comparison Service and relevant clinical data, to identify optimum value for money procurement choices, considering both outcomes and cost/price.	GIRFT	For continual action throughout the GIRFT programme.
	b Identify opportunities for improved value for money, including the development of benchmarks and specifications. Locate sources of best practice and procurement excellence, identifying factors that lead to the most favourable procurement outcomes.	GIRFT	For continual action throughout the GIRFT programme.
	c Use Category Towers (CTs) to benchmark and evaluate products and seek to rationalise and aggregate demand with other trusts to secure lower prices and supply chain costs.	GIRFT	Upon completion of 1B.

Litigation

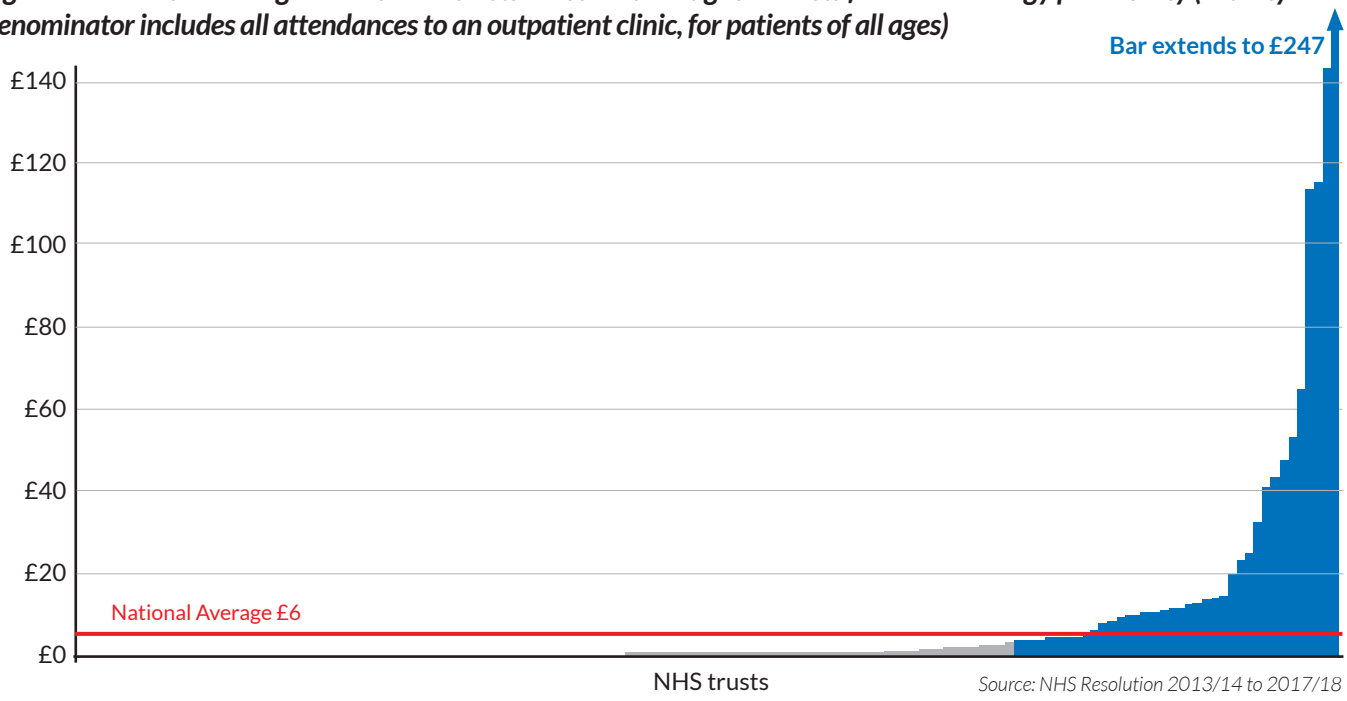
Reducing the impact of litigation

As well as looking at addressing variation in clinical practice, the GIRFT programme teams have been asked to examine the impact and causes of litigation in their field with a view to reducing the frequency of litigation and, more importantly, the incidents that lead to it. Ensuring clinical staff have the opportunity to learn from claims, in conjunction with complaints, Serious Incidents (SIs) / Patient Safety Incidents and inquests, will improve patient care and reduce costs both in terms of litigation itself and management of the resulting complications of potential incidents.

Variation in average litigation costs

NHS Resolution data shows that clinical negligence claims in endocrinology estimated at between £3.8m and £11.5m per year over the last five years making the national average estimated cost of litigation per outpatient attendance £6. There are vast differences between providers: the best performer is estimated to cost £0 per activity, while one provider is expected to generate an average of £247 of litigation costs per activity.

Figure 21: Variation in England between trusts in estimated litigation costs for endocrinology per activity (activity denominator includes all attendances to an outpatient clinic, for patients of all ages)



Source: NHS Resolution 2013/14 to 2017/18

The year-on-year data shows an overall increase in claim volume and a steep increase in estimated costs of claims since 2015/16 mirroring the increasing cost of clinical negligence claims across the NHS. Effective learning from claims allows good practice to be shared and has the potential to reduce claims and ensure resources are not unnecessarily diverted from frontline care. Most importantly, this learning means more patients receive the right care first time, with the cost savings and improved outcomes this implies.

Table 5: Volume and cost of medical negligence claims against Endocrinology notified to NHS Resolution 2013/14 to 2017/18

Year	No. of claims	% change in claims no.	Total cost (£m) (including estimated and reserve values)	% change in total cost
2013/14	38	-	£11.13	-
2014/15	35	-8%	£ 6.99	-37%
2015/16	30	-14%	£3.77	-46%
2016/17	38	27%	£9.88	162%
2017/18	42	11%	£11.48	16%
Total	183	-	£43.24	-

Source data: NHS Resolution 2013/14 to 2017/18

Claims trends and causes

The most common causes for claims were related to 'Treatment' (92 claims, 43%), 'Diagnosis' (75 claims, 35%), 'Surgery' (23 claims, 11%) and 'Infection/sepsis' (5 Claims, 2%).

Of the 92 claims under 'Treatment', 17 (8%) were identified as 'Medicine error', of which seven related to steroid prescriptions. The move to a more digitised UK healthcare system and electronic prescribing in hospitals has great potential to improve patient safety through reduction of medicine errors and adverse drug events. Policymakers and end users should carefully consider implementation of such systems, particularly support for front-line staff, intraoperability with other clinical systems, and network and hardware support when deploying e-prescribing systems in trusts.

Of the 75 claims under 'Diagnosis', 19 related to failure to perform tests/interpret results leading to a failure or delay in diagnosis. Many of these claims can be addressed through training. The management of complex endocrine patients has become increasingly specialised and training in complex specialist endocrinology diagnostics and treatment requires extensive exposure. In April 2019, the Association of British Clinical Diabetologists and Society for Endocrinology issued a statement on training, which included a recommendation that training include a minimum of two years (or equivalent) protected specialty time. Other factors driving claims related to diagnosis include the insufficient capacity to meet the demand for endocrinology.

Claims relating to a surgical procedure totalled 11%, indicating clear coding error to specialty. Every effort should be made to improve the accuracy of coding to facilitate learning from claims. It is the expectation of the GIRFT programme that many of these coding errors will be corrected in response to the five-point plan included in the recommendations of this report and the GIRFT litigation data pack which contains the references of these claims for endocrine departments to review.

Sepsis is a potentially life-threatening condition but, when diagnosed early with prompt treatment, outcomes are generally favourable. Five claims (2%) were related to infection/sepsis. In July 2016, NICE (NG51) published a guideline outlining immediate actions required for suspected cases of sepsis and a framework for risk assessment, treatment and follow-up. Clinicians should take the guideline into account when exercising their judgement in a clinical setting.[57]

In all, 15 claims (7%) related to inadequate nursing care/assistance and three (1%) to inappropriate discharge from hospital. When reviewing claims, trusts should include all clinical staff involved in patient care in their governance structure to maximise and share learning from claims.

It was clear during GIRFT visits that many providers had little knowledge of the claims against them. This includes some with high litigation costs per admission. As a consequence, very few lessons have been learnt from the claims to inform future practice. Further work is needed at both a local and national level to analyse claims in order to maximise this opportunity to improve patient care.

[57] *National Institute for Health and Care Excellence (NICE) (2016) Sepsis: Recognition, diagnosis and early management, https://www.nice.org.uk/guidance/ng51*

Recommendations

Recommendation	Actions	Owners	Timescale
17. Reduce litigation costs by application of the GIRFT Programme's five-point plan.	**a** Clinicians and trust management to assess their benchmarked position compared to the national average when reviewing the estimated litigation cost per unit of activity.	Trusts	For immediate action
	b Clinicians and trust management to regularly discuss with the legal department or claims handler the claims submitted to NHS Resolution included in the data set to confirm correct coding to that department. Inform NHS resolution of any claims that are not coded correctly to the appropriate specialty via CNST.Helpline@resolution.nhs.uk	Trusts	Upon completion of 17A
	c Once claims have been verified, clinicians and trust management to further review claims in detail, including expert witness statements, panel firm reports and counsel advice as well as medical records to determine where patient care or documentation could be improved. If the legal department or claims manager needs additional assistance with this, each trust's panel firm should be able to provide support.	Trusts	Upon completion of 17B
	d Claims should be triangulated with learning themes from complaints, inquests and serious incidents (SIs)/Patient Safety Incidents (PSIs) and, where a claim has not already been reviewed as SI/PSI, we recommend that this is carried out to ensure no opportunity for learning is missed. The findings from this learning should be shared with all front-line clerical staff in a structured format at departmental/ directorate meetings (including multidisciplinary team meetings where appropriate).	Trusts	Upon completion of 17C
	e Where trusts are outside the top quartile of trusts for litigation costs per activity, GIRFT will be asking national clinical leads and regional teams to follow up and support trusts in the steps taken to learn from claims. Clinical leads and regional team directors will also be able to share examples of good practice with trusts.	Trusts	For continual action throughout GIRFT programme

Activity and notional financial opportunities

This report sets out a series of ways to improve delivery of NHS endocrinology services using the existing resources available to the specialty.

While the impact in some areas is hard to measure, in others there is a clear tangible benefit.

Potential benefits

Improvements to the patient experience would be seen in shorter stays, improved pathways (fewer duplicated tests and clearer referral criteria for specialised/non-specialised services), reduced travel for outpatient and follow-up visits and potentially shorter waiting times. All of these also benefit providers by freeing up resources for other purposes.

Notional financial opportunity

The notional financial opportunity could be between £5.5m and £9m a year, in addition to potential cost savings in procurement.

These figures provide a financial value for a range of efficiency savings, which may not be cash releasing.

The figures are based on a selection of metrics (shown in Table 6) and provide an indication of what may be possible. The metrics do not represent a comprehensive set of all opportunities discussed in the report.

The gross financial opportunities put an estimated value on the resources associated with variation based on all providers achieving at least the average or best quartile performance. The opportunities are not cash-releasing efficiency savings.

In addition to the specific areas outlined in the table, the report has identified a total spend of £43m on litigation over a five-year period. Implementation of the GIRFT Programme's five-point plan should improve patient safety and reduce litigation costs for endocrinology patients.

Further opportunities

The opportunity values shown are for illustration only. Individual providers and clinicians should assess their own services to determine the unwarranted variation that exists and the associated opportunity. Their assessment will help them to prioritise the service changes that they wish to deliver.

Individual providers may also have other opportunities that are not included here.

Table 6: Activity opportunities and notional financial opportunities in endocrinology

Improvement	Standard			Target		
	Target	Activity opportunity*	Gross notional financial opportunity**	Target	Activity opportunity*	Gross notional financial opportunity**
Reduce length of stay for parathyroid surgery for primary hyperparathyroidism *(Recommendation 5Ai)* Opportunity: bed day saving, parathyroid surgery for primary hyperparathyroidism. *Base data: April 17 - Mar 18.* *Cost estimated on endocrinology (KA and KC) HRGs - average elective and non-elective excess bed day cost.*	*Clinical recommendation* 90% of admissions 0 night length of stay (day case)	2,300 bed days	£0.78m	*Clinical recommendation - as standard* 90% of admissions 0 night length of stay (day case)	2,300 bed days	£0.78m

Note: The financial impact related to Recommendation 5Aii (reduced LoS for Thyroid Lobectomy) has not been included in the table above as the gross estimated savings calculated were not significant..

Table 6: Activity opportunities and notional financial opportunities in endocrinology (continued)

Improvement	Standard			Target		
	Target	Activity opportunity*	Gross notional financial opportunity**	Target	Activity opportunity*	Gross notional financial opportunity**
Reduce length of stay for total thyroidectomy *(Recommendation 5Aiii)* Opportunity: bed day saving, total thyroidectomy patients. *Base data: April 17 - Mar 18.* *Cost estimated on endocrinology (KA and KC) HRGs - average elective and non-elective excess bed day cost.*	*Clinical recommendation* 90% of admissions 2 nights or less length of stay (75% 1 night, 15% 2 nights)	3,200 bed days	£1.08m	*Clinical recommendation - as standard* 90% of admissions 2 nights or less length of stay (75% 1 night, 15% 2 nights)	3,200 bed days	£1.08m
Increase proportion of patients discharged at first outpatient appointment (through implementation of CAS services) *(Recommendation 9)* Opportunity: reduction in endocrinology follow-up outpatient attendances. *Base data: April 17 - Mar 18.* *Cost estimated based on endocrinology follow-up outpatient attendance.*	*50% towards national average* 50% move towards national average of 20% discharged at first OP attendance	3,500 Follow-up outpatient attendances	£0.58m	*National average* 20% discharged at first outpatient attendance	6,900 Follow-up outpatient attendances	£1.14m
Better management of hospital follow-up outpatient attendances *(Recommendation 10)* Opportunity: improve first to follow-up outpatient ratio i.e. reduce follow-ups. *Base data: April 17 - Mar 18.* *Cost estimated based on endocrinology follow-up outpatient attendance.* *Note: The activity savings calculated above, reduction in follow-up attendances, have been netted-off here to avoid double counting.*	*50% towards national average*			*National average*		
a) Specialist*** providers of endocrinology services	50% move towards 3.3 new to follow-up outpatient ratio	9,600 Follow-up outpatient attendances	£1.58m	3.3 new to follow-up outpatient ratio	19,200 Follow-up outpatient attendances	£3.16m
b) Non-specialist*** providers of endocrinology services	50% move towards 2.61 new to follow-up outpatient ratio	9,200 Follow-up outpatient attendances	£1.51m	2.61 new to follow-up outpatient ratio	18,300 Follow-up outpatient attendances	£3.01m
Total			**£5.53m**			**£9.17m**

* *Activity opportunities are annual figures, based on one year of activity data*

** *Costing financial opportunity: unless otherwise stated, cost estimates are based on national average of 17/18 reference costs, uplifted to 20/21 pay and prices using tariff inflation.*

*** *Providers are self-described as specialist or non-specialist.*

About the GIRFT programme

Getting It Right First Time (GIRFT) is a national programme designed to improve medical care within the NHS.

Funded by the Department of Health and Social Care and jointly overseen by NHS England and NHS Improvement, and the Royal National Orthopaedic Hospital NHS Trust, it combines wide-ranging data analysis with the input and professional knowledge of senior clinicians to examine how things are currently being done and how they could be improved.

Working to the principle that a patient should expect to receive equally timely and effective investigations, treatment and outcomes wherever care is delivered, irrespective of who delivers that care, GIRFT aims to identify approaches from across the NHS that improve outcomes and patient experience, without the need for radical change or additional investment. While the gains for each patient or procedure may appear marginal they can, when multiplied across an entire trust – and even more so across the NHS as a whole – deliver substantial cumulative benefits.

The programme was first conceived and developed by Professor Tim Briggs to review elective orthopaedic surgery to address a range of observed and undesirable variations in orthopaedics. In the 12 months after the pilot programme, it delivered an estimated £30m-£50m savings in orthopaedic care – predominantly through changes that reduced average length of stay and improved procurement.

The same model is now being applied in over 40 different areas of clinical practice. It consists of four key strands:

- a broad data gathering and analysis exercise, performed by health data analysts, which generates a detailed picture of current national practice, outcomes and other related factors;
- a series of discussions between clinical specialists and individual hospital trusts, which are based on the data – providing an unprecedented opportunity to examine individual trust behaviour and performance in the relevant area of practice, in the context of the national picture. This then enables the trust to understand where it is performing well and what it could do better – drawing on the input of senior clinicians;
- a national report, that draws on both the data analysis and the discussions with the hospital trusts to identify opportunities for NHS-wide improvement;
- an implementation phase where the GIRFT team supports providers to deliver the improvements recommended.

GIRFT and other improvement initiatives

GIRFT is part of an aligned set of workstreams within the Operational Productivity Directorate of NHS England and NHS Improvement. It is the delivery vehicle for one of several recommendations made by Lord Carter in his February 2016 review of operational efficiency in acute trusts across England. As well as support from the Department of Health and Social Care and NHS England and NHS Improvement, it has the backing of the Royal Colleges and professional associations.

GIRFT has a significant and growing presence on the Model Hospital portal, with its data-rich approach providing the evidence for hospitals to benchmark against expected standards of service and efficiency. The programme also works with a number of wider NHS programmes and initiatives which are seeking to improve standards while delivering savings and efficiencies, such as NHS RightCare, the Evidence-Based Interventions Programme, acute care collaborations (ACCs), and sustainability and transformation partnerships (STPs).

Implementation

GIRFT has developed an implementation programme designed to help trusts and their local partners to address the issues raised in trust data packs and the national specialty reports to improve quality. The GIRFT team provides support at a local level, advising on how to reflect the national recommendations into local practice and supporting efforts to deliver any trust specific recommendations emerging from the GIRFT visits.

GIRFT also helps to disseminate best practice across the country, matching up trusts who might benefit from collaborating in selected areas of clinical practice. Through all its efforts, local or national, the GIRFT programme strives to embody the 'shoulder to shoulder' ethos that has become GIRFT's hallmark, supporting clinicians nationwide to deliver continuous quality improvement for the benefit of their patients.

Future plans for collaborative working

In the future, regional visits with endocrinologists and endocrine surgeons should aim to improve surgical numbers in the area of thyroid, parathyroid, adrenal and pituitary surgery, to attain the national guidelines, to decrease costs and to improve outcomes and lessen complications.

The Society for Endocrinology and the NHS England Clinical Reference Group should work together to:

1. Delineate criteria for referral into secondary and specialist care and the necessary tests involved.
2. Delineate further protocols in secondary and specialist care and improve in and out criteria.
3. Recommend regional centres for adrenal venous sampling (AVS) and for inferior sinus sampling to rationalise numbers and improve outcomes.
4. Define hubs and spokes in adrenal, pituitary, thyroid and parathyroid surgery.
5. Delineate the differentiation of secondary and specialist care in order to develop service level agreements.
6. Develop a list of endocrine outpatient day case tests.

Glossary

Acute care collaborations (ACCs)
A group of NHS trusts working together to improve their clinical and financial viability in delivering acute care, reducing variation in care and efficiency. For example, hospitals working together as groups or chains, specialty franchises and clinical networks. Part of NHS England's new care models programme.

https://www.england.nhs.uk/new-care-models/about/acute-care-collaboration/

Adrenal venous sampling (AVS)
Venous sampling is a diagnostic procedure that uses imaging guidance to insert a catheter into a specific vein and remove blood samples for laboratory analysis. Abnormal levels of certain substances in the blood may indicate the presence of disease in the organ or tissue that produces them.

British Association of Day Surgery (BADS)
The professional association for consultant anaesthetists and surgeons performing day surgery procedures.

https://daysurgeryuk.net/en/home/

British Association of Endocrine and Thyroid Surgeons (BAETS)
The representative body of British surgeons who have a specialist interest in surgery of the endocrine glands (thyroid, parathyroid and adrenal).

www.baets.org.uk/about-us/

Casemix
The type or mix of patients, categorised by a variety of measures, including: demographics, disease type and severity, and the diagnostic or therapeutic procedures performed.

Category Towers (CTs)
The procurement function of the NHS Supply Chain operating model. The 11 category towers undertake clinical evaluation of products and run procurement processes, with each one specialising in a particular area of products or services, for example medical equipment.

www.supplychain.nhs.uk/sccl

Clinical Commissioning Groups (CCGs)
Clinically led statutory NHS bodies responsible for the planning and commissioning of healthcare services for their local area.

www.nhscc.org/ccgs/

Commissioning
The various processes that identify the health needs of a population, such as a local area, and purchase services to meet those needs.

Co-morbidity
The simultaneous presence of two or more chronic (long-term) diseases, or conditions in a patient.

Day of surgery admission
Admission to hospital on the same day that surgery takes place.

Day case/day case surgery
Surgery where the patient is electively admitted and discharged on the same day, without the use of a hospital bed or overnight stay and thus does not become an inpatient.

Elective (surgery or care)
Surgery or care that is planned, rather than carried out as an emergency (non-elective).

Healthcare Resource Group (HRG)
Standard groupings of clinically similar treatments that use common levels of healthcare resource. HRGs help organisations to understand their activity in terms of the types of patients they care for and the treatments they undertake.

Hospital Episode Statistics (HES)
Data on all admissions, out-patient appointments and A&E attendances at NHS hospitals in England. HES data aims to collect a detailed record for each 'episode' of admitted patient care commissioned by the NHS and delivered in England, by either an NHS hospital or the independent sector. HES data is used in calculating what hospitals are paid for the care they deliver.

Integrated care systems
NHS organisations, in partnership with local councils and others, taking collective responsibility for managing resources, delivering NHS standards, and improving the health of the population they serve.

www.england.nhs.uk/integratedcare/integrated-care- systems

Length of stay
The length of an inpatient episode of care, calculated from the day of admission to day of discharge, and based on the number of nights spent in hospital.

Model Hospital

A free digital tool provided by NHS Improvement to enable trusts to compare their productivity and identify opportunities to improve. The tool is designed to support NHS provider trusts to deliver the best patient care in the most efficient way.

https://model.nhs.uk

Multidisciplinary team (MDT)

A team of healthcare professionals from different disciplines.

National Clinical Improvement Programme (NCIP)

A programme to provide both team- and clinical-level activity and metrics about the whole of a clinician's practice. It aims to provide a single point of access to existing information from Hospital Episode Statistics (HES), audit and registry, and private sector.

https://gettingitrightfirsttime.co.uk/associated- projects/ncip/

National Institute for Health and Care Excellence (NICE)

Provides evidence-based guidance, advice, quality standards, performance metrics and information services for health, public health and social care.

www.nice.org.uk

NHS Resolution (formerly NHS Litigation Authority)

Provides expertise to the NHS to resolve negligence concerns, share learning for improvement and preserve resources for patient care. NHS Resolution is an 'arm's length' body of the Department of Health and Social Care. This means it is an independent body, but can be subject to ministerial direction.

www.resolution.nhs.uk

NHS RightCare

An NHS England programme that works locally with systems (bodies involved in delivering services) to diagnose issues, develop solutions and deliver improvements.

www.england.nhs.uk/rightcare

NHS Supply chain

An organisation that provides healthcare products and supply chain services to the NHS, including procurement, logistics, e-commerce, and customer and supplier support.

www.supplychain.nhs.uk

Patient Level Information and Costing Systems (PLICS)

A system of collecting and deriving costs at the patient level.

Payment by Results (PbR)

The payment system in England used by healthcare commissioners to pay healthcare providers for each patient seen or treated. The system takes account of the complexity of the patient's healthcare needs.

Petrosal venous sampling

Venous sampling is a diagnostic procedure that uses imaging guidance to insert a catheter into a specific vein and remove blood samples for laboratory analysis. Abnormal levels of certain substances in the blood may indicate the presence of disease in the organ or tissue that produces them.

Purchase Price Index and Benchmarking (PPIB)

A system to collect procurement data from NHS trusts that enables trusts to compare and benchmark data.

Reference costs

Reference costs are the average unit cost to the NHS of providing defined services to NHS patients in England in a given financial year. They show how NHS providers spend money to provide healthcare to patients. NHS providers submit reference costs annually.

Society of British Neurosurgeons (SBNS)

The professional body for British neurosurgeons.

https://www.sbns.org.uk/

Spell

A period of healthcare, for example a period spent in hospital or admission to hospital.

Sustainability and transformation partnerships (STPs)

Partnerships between NHS providers, Clinical Commissioning Groups (CCGs), local authorities and other health and care services to develop proposals for how local areas will work together to improve health and care for their local population. There are 44 STPs.

www.england.nhs.uk/integratedcare/stps

Acknowledgements

It has been a hugely rewarding exercise as well as enjoyable and intellectually stimulating to go round all the departments of endocrinology in our specialty, together with the opportunity provided to improve care and patient management within our specialty. The first thing to say is what an incredible specialty it is and how hard-working over and above the odds endocrinologists are in their wish to provide excellent care for endocrine patients.

Tim Briggs provided this opportunity in his GIRFT initiative and he and Rachel Yates together with Nicola Joyce have been incredibly supportive throughout the process.

From the outset it was clear that this was very well organised. Jamie Day gave a very strong sense of this at the very first meeting and has continued to be hugely supportive and full of common sense. Peter Stewart-Sandeman and Jenny Littlewood provided inestimable support and were outstanding travelling companions, organising the visits with a high degree of efficiency, conflating everything to perfection. James Murphy was incredibly helpful putting all the data together. Our report was guided with gubernatorial wonder by Kathleen Reinoga.

Diane Stafford was masterful in capturing the kernel of our report.

The trusts were almost invariably efficient in responding to our needs and I got a lot of support from the Society for Endocrinology and its members. In particular, I would like to mention John Newell-Price and Antonia Brooke who were a reliable, rapidly responsive sounding board and source of good advice throughout.

As clinical lead it was a wonderful opportunity to see and meet my colleagues and work with them to the benefit of our specialty.

I would particularly like to acknowledge Sally my long-suffering and ever supportive wife. Always full of common sense and intelligent practical advice and support.

Now it's up to us endocrinologists to put it all into action!

Data and copyright acknowledgement

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- BAETS
- UKRETS

We are grateful to NHS Resolution for the litigation data provided and to John Machin and Cherrie Ho for their kind authorship of the litigation section in this report.

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Appendix 1: List of trusts visited during endocrinology deep dives

The GIRFT endocrinology team visited 126 trusts, which have become 125 following the merger of Central Manchester University Hospitals NHS Foundation Trust and University Hospital of South Manchester NHS Foundation Trust to form Manchester University NHS Foundation Trust.

Aintree University Hospitals NHS Foundation Trust

Airedale NHS Foundation Trust

Ashford & St Peter's Hospitals NHS Foundation Trust

Barking, Havering and Redbridge University Hospitals NHS Trust

Barnsley Hospital NHS Foundation Trust

Barts Health NHS Trust

Basildon and Thurrock University Hospitals NHS Foundation Trust

Bedford Hospital NHS Trust

Blackpool Teaching Hospitals NHS Foundation Trust

Bolton NHS Foundation Trust

Bradford Teaching Hospitals NHS Foundation Trust

Brighton and Sussex University Hospitals NHS Trust

Buckinghamshire Healthcare NHS Trust

Calderdale and Huddersfield NHS Foundation Trust

Cambridge University Hospitals NHS Foundation Trust

Chelsea and Westminster Hospital NHS Foundation Trust

Chesterfield Royal Hospital NHS Foundation Trust

Colchester Hospital University NHS Foundation Trust

Countess of Chester Hospital NHS Foundation Trust

County Durham and Darlington NHS Foundation Trust

Croydon Health Services NHS Trust

Dartford and Gravesham NHS Trust

Doncaster and Bassetlaw Hospitals NHS Foundation Trust

Dorset County Hospital NHS Foundation Trust

East and North Hertfordshire NHS Trust

East Cheshire NHS Trust

East Kent Hospitals University NHS Foundation Trust

East Lancashire Hospitals NHS Trust

East Sussex Healthcare NHS Trust

Epsom and St Helier University Hospitals NHS Trust

Frimley Health NHS Foundation Trust

George Eliot Hospital NHS Trust

Gloucestershire Hospitals NHS Foundation Trust

Great Western Hospitals NHS Foundation Trust

Guy's and St Thomas' NHS Foundation Trust

Hampshire Hospitals NHS Foundation Trust

Harrogate and District NHS Foundation Trust

Homerton University Hospital NHS Foundation Trust

Hull University Teaching Hospitals NHS Trust

Imperial College Healthcare NHS Trust

Isle of Wight NHS Trust

James Paget University Hospitals NHS Foundation Trust

Kettering General Hospital NHS Foundation Trust

King's College Hospital NHS Foundation Trust

Kingston Hospital NHS Trust

Lancashire Teaching Hospitals NHS Foundation Trust

Leeds Teaching Hospitals NHS Trust

Lewisham & Greenwich NHS Trust

London North West University Healthcare NHS Trust

Luton and Dunstable University Hospital NHS Foundation Trust

Maidstone and Tunbridge Wells NHS Trust

Manchester University NHS Foundation Trust

Medway NHS Foundation Trust

Norfolk and Norwich University Hospitals NHS Foundation Trust

North Bristol NHS Trust

North Cumbria Integrated Care NHS Foundation Trust

North Middlesex University Hospital NHS Trust

North West Anglia NHS Foundation Trust

Northampton General Hospital NHS Trust

Northern Lincolnshire & Goole Hospital NHS Foundation Trust

Northumbria Healthcare NHS Foundation Trust

Nottingham University Hospitals NHS Trust

Oxford University Hospitals NHS Trust

Portsmouth Hospitals NHS Trust

Royal Berkshire NHS Foundation Trust

Royal Cornwall Hospitals NHS Trust

Royal Devon and Exeter NHS Foundation Trust

Royal Free London NHS Foundation Trust

Royal Surrey County Hospital NHS Foundation Trust

Royal United Hospitals Bath NHS Foundation Trust

Salford Royal NHS Foundation Trust

Salisbury NHS Foundation Trust

Sandwell and West Birmingham Hospitals NHS Trust

Sheffield Teaching Hospitals NHS Foundation Trust

Sherwood Forest Hospitals NHS Foundation Trust

South Tees Hospitals NHS Foundation Trust

South Tyneside and Sunderland NHS Foundation Trust

South Warwickshire NHS Foundation Trust

Southend University Hospital NHS Foundation Trust

Southport and Ormskirk Hospital NHS Trust

St George's University Hospitals NHS Foundation Trust

St Helens and Knowsley Teaching Hospitals NHS Trust

Surrey and Sussex Healthcare NHS Trust

Tameside and Glossop Integrated Care NHS Foundation Trust

Taunton and Somerset NHS Foundation Trust

The Christie NHS Foundation Trust

The Dudley Group NHS Foundation Trust

The Hillingdon Hospitals NHS Foundation Trust

The Ipswich Hospital NHS Trust

The Mid Yorkshire Hospitals NHS Trust

The Newcastle upon Tyne Hospitals NHS Foundation Trust

The Pennine Acute Hospitals NHS Trust

The Princess Alexandra Hospital NHS Trust

The Queen Elizabeth Hospital King's Lynn NHS Foundation Trust

The Rotherham NHS Foundation Trust

The Royal Bournemouth & Christchurch Hospitals NHS Foundation Trust

The Royal Liverpool and Broadgreen University Hospitals NHS Trust

The Royal Marsden NHS Foundation Trust

The Royal Wolverhampton Hospitals NHS Trust

The Shrewsbury and Telford Hospital NHS Trust

Torbay and South Devon Healthcare NHS Foundation Trust

United Lincolnshire Hospitals NHS Trust

University College London Hospitals NHS Foundation Trust

University Hospital Southampton NHS Foundation Trust

University Hospitals Birmingham NHS Foundation Trust

University Hospitals Bristol NHS Foundation Trust

University Hospitals Coventry and Warwickshire NHS Trust

University Hospitals of Derby and Burton NHS Foundation Trust

University Hospitals of Leicester NHS Trust

University Hospitals of Morecambe Bay NHS Foundation Trust

University Hospitals of North Midlands NHS Trust

University Hospitals Plymouth NHS Trust

Walsall Healthcare NHS Trust

Warrington and Halton Hospitals NHS Foundation Trust

West Hertfordshire Hospitals NHS Trust

West Suffolk NHS Foundation Trust

Western Sussex Hospitals NHS Trust

Weston Area Health NHS Trust

Whittington Health NHS Trust

Wirral University Teaching Hospital NHS Foundation Trust

Worcestershire Acute Hospitals NHS Trust

Wrightington, Wigan & Leigh NHS Foundation Trust

Wye Valley NHS Trust

Yeovil District Hospital NHS Foundation Trust

York Teaching Hospital NHS Foundation Trust

Appendix 2: Volume-outcome relationships in total thyroidectomy: Summary of key findings for the national report (W K Gray 11th July 2019)

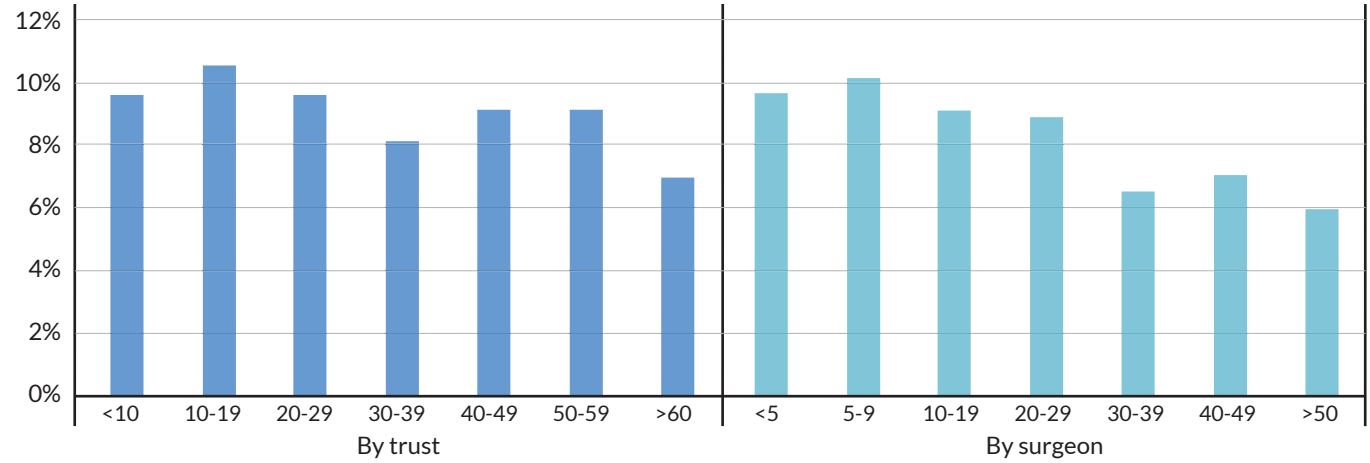
In thyroid surgery, there is evidence from peer-reviewed publications that surgeon volume is linked to outcomes for patients. Adam *et al*[58] identified < 26 procedures annum as associated with an increased complication rate. Nouraei *et al*[59] used English Hospital Episode Statistics (HES) data from 2004 to 2012 and identified length of stay, vocal palsy and hypocalcaemia to be associated with low volume surgeons, with > 30 procedures per annum consistently protective. Adkisson et *al*.[60] also identified > 30 as a cut off for surgeon volumes with regard to outcomes for completeness of resection and the appropriateness of the operation undertaken.

In June 2019 Aspinall *et al*[61] published a paper using data on 25,038 thyroidectomies from the UK Registry of Endocrine and Thyroid Surgery (UKRETS) and identified a link between surgeon volume and permanent hypoparathyroidism and recurrent laryngeal nerve palsy and suggested an annual minimum number of thyroid operations of 50.

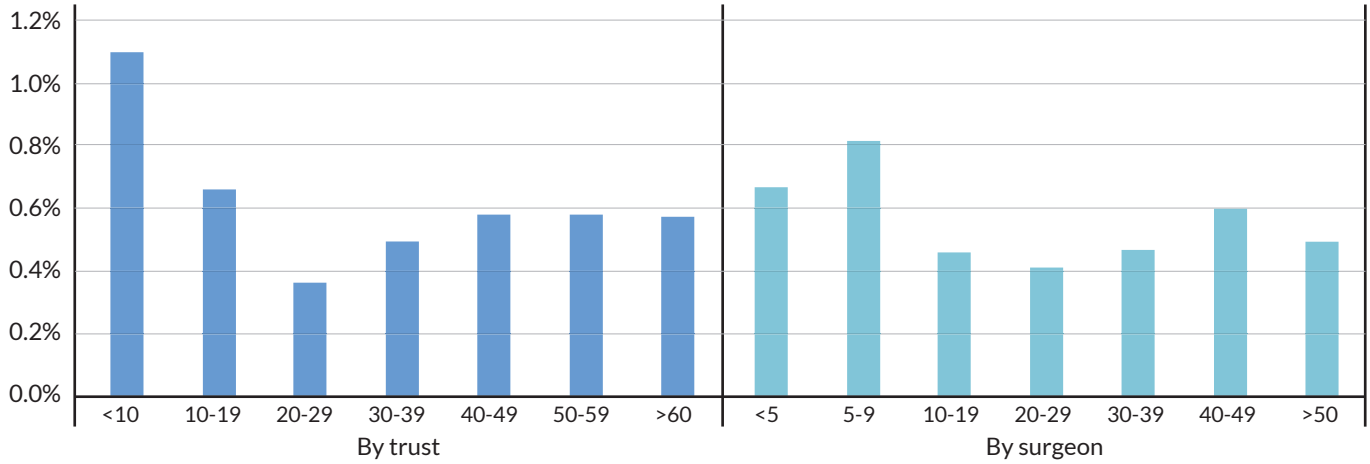
HES data: Change in number of procedures since 2013 shows no evidence of move towards centralisation.

Figure 22: Crude (unadjusted) relationship between volume and outcome

a) Hospital readmission within 90 days of discharge



b) Diagnosis of hypoparathyroidism within 90 days of admission



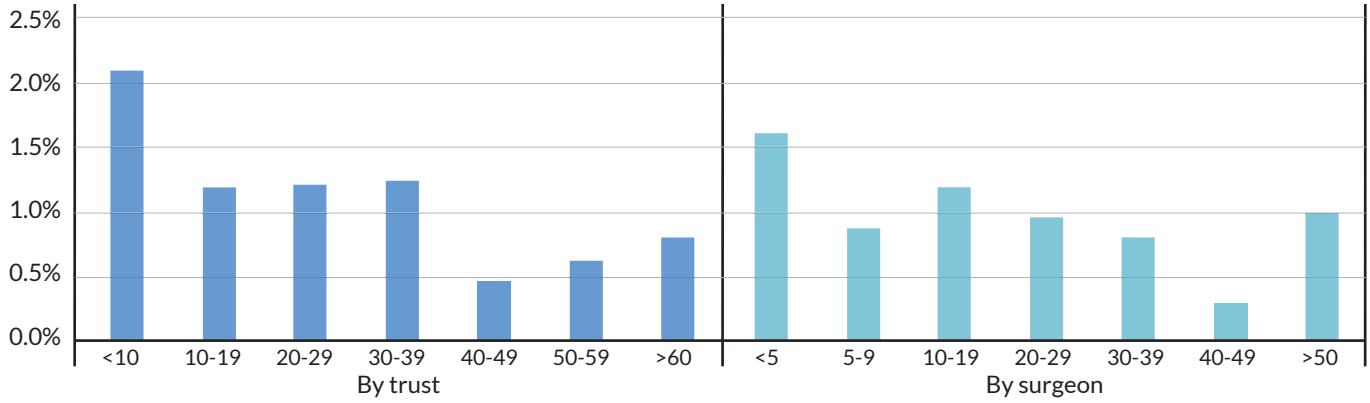
[58] *M. A. Adam, S. Thomas, L. Youngwirth et al.(2017), Is there a minimum number of thyroidectomies a surgeon should perform to optimize patient outcomes? Ann Surg 265(2): 402–407 (cited in W. K. Gray Volume–outcome relationships).*

[59] *S. A Nouraei, J. S. Virk, S. E. Middleton et al. (2017), A national analysis of trends, outcomes and volume-outcome relationships in thyroid surgery. Clin Otolaryngol 42(2): 354–365 (cited in W. K. Gray, Volume–outcome relationships).*

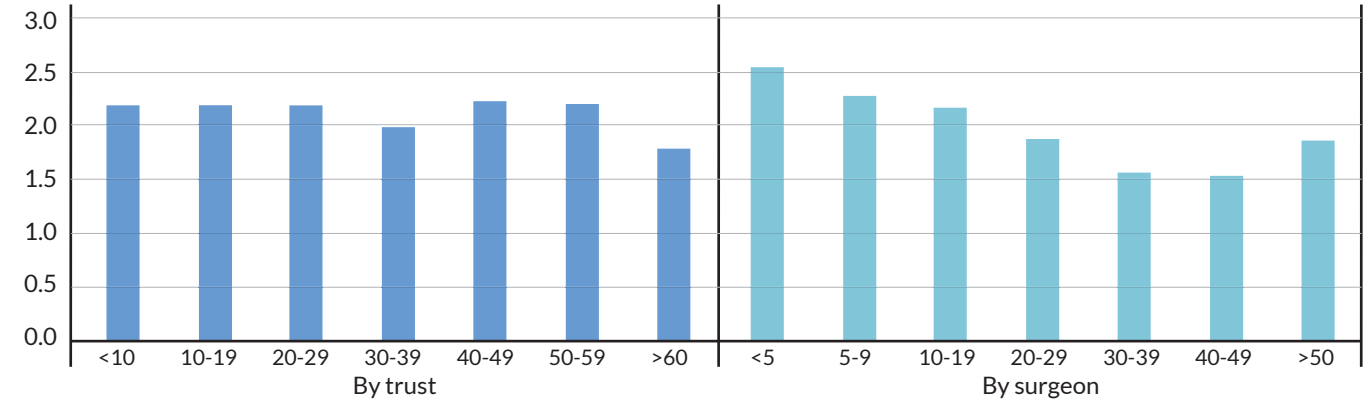
[60] *C. D. Adkisson, G. M. Howell, K. L McCoy et al. Surgeon volume and adequacy of thyroidectomy for differentiated thyroid cancer. Surgery 2014; 156(6): 1453–1459; discussion 60 (cited in W. K. Gray, Volume–outcome relationships).*

[61] *S. Aspinall, D. Owesis and D. Chadwick (2019), Effect of surgeons' annual operative volume on the risk of permanent hypoparathyroidism, recurrent laryngeal nerve palsy and haematoma following thyroidectomy: analysis of United Kingdom Registry of Endocrine and Thyroid Surgery (UKRETS). Langenbecks Arch Surg; 404(4): 421–430 (cited in W. K. Gray, Volume–outcome relationships).*

c) Diagnosis of vocal paralysis within 90 days of admission



d) Mean length of hospital stay (days)



After adjusting for the effects of age, sex, frailty, year of admission, greater emergency readmission rate was significantly associated with surgeon volumes of less than ten per annum (odds ratio (OR) = 1.734 and 1.656 for these lower-volume categories relative to highest-volume category) and trust volumes of less than 30 per annum (OR = 1.421 to 1.593 for these lower-volume categories). Receiving a post-surgery diagnosis of hypoparathyroidism was associated with increasing frailty levels, but neither trust or surgeon volumes. Receiving a post-surgery diagnosis of vocal paralysis was associated with financial year, age band and trust volumes of less than ten per annum (OR = 3.205). Finally, hospital length of stay of greater than the median was significantly associated with greater age, greater frailty levels, being seen in a less recent financial year and surgeon volumes of less than ten per annum (OR = 4.685 and 6.386 for these lower volume categories). When both surgeon volume and trust volume were forced into the model predicting readmission at 90 days, only surgeon volume was significant, suggesting this was the dominant predictor.

Change in number of procedures over time and evidence of movement towards centralisation

As shown in Table 7, there was no evidence of centralisation within larger volume trusts or larger volume surgeons over time. *Indeed, mean volume per trust and per surgeon declined slightly over the study period.*

A note from the authors, Professor Wass and Mr Lansdown:

There are limitations to using HES data when exploring outcomes after surgery. The recommendations made in our report are based on analysis of data from HES, the UKRETS database, from the questionnaires returned by trusts and peer reviewed literature.

From the data we have seen three things stand out. Firstly, outcomes and lengths of stay are generally better for the high-volume centres. Second, a comparison of HES and UKRETS data suggests that, on average, surgeons who enter data into the national audit achieve better outcomes. Finally, some surgeons performing acceptable volumes do not always get the best results. Therefore it is not enough to focus only on volume, the audit of outcomes is essential if they are to be improved.

Taking all of this into account we have recommended changes to surgical practice and minimum volumes of surgery that are both sensible and achievable.

Table 7: Change in mean surgical volume over time

	2013-14	2014-15	2015-16	2016-17	2017-18
Total volume	3205	3238	3073	3098	2895
Mean volume per trust	26.3	26.3	24.8	25.6	24.5
Mean volume per surgeon	12.5	12.0	11.4	11.6	11.6

Table 8: Use of tracheostomy within surgeon volume categories

Procedures per annum per surgeon	Permanent tracheostomy (n = 2)	Temporary tracheostomy (n = 33)	No tracheostomy (n = 15,509)
< 5	1 (50.0%)	8 (24.2%)	1790 (11.5%)
5-9	1 (50.0%)	3 (9.1%)	3188 (20.6%)
10-19	0	9 (27.3%)	4320 (27.9%)
20-29	0	7 (21.2%)	3198 (20.6%)
30-39	0	4 (12.1%)	1494 (9.6%)
40-49	0	1 (3.0%)	672 (4.3%)
≥ 50	0	1 (3.0%)	812 (5.2%)

Analysis of UKRETS data

Data were available for 256 surgeons across 9,432 total thyroidectomies. Outcomes within each of the volume categories are summarised in Table 9. There was a clear trend towards length of stay > 2 days at lower volumes and some evidence of a trend towards lower readmission rates at high volume. However, there were no obvious trends for the outcomes of re-exploration of the neck for bleeding or mortality.

Table 9: Outcomes across volume categories (UKRETS)

Surgeon volume	Procedures	Surgeons	Total thyroidectomy stay > 2 days	Related readmission	Re-exploration of the neck for bleeding	In-hospital mortality
< 5	952	140	30.3%	1.5%	1.0%	0.04%
5-9	1005	35	27.0%	2.1%	0.8%	0.03%
10-19	2182	40	16.9%	2.0%	1.2%	0.01%
20-29	2565	26	19.3%	1.7%	1.2%	0.07%
30-39	949	7	18.5%	1.7%	1.2%	0.00%
40-49	708	4	13.3%	1.2%	1.0%	0.07%
≥ 50	1071	4	5.8%	1.0%	1.6%	0.05%

After adjusting for case load pathology mix (cancer, colloid goitre, Graves' disease, other) length of stay > 2 days was significantly associated with surgeon volume, although other outcomes were not. This broadly supported the findings from analysis of the HES data.

Appendix 3: BADS-recommended lengths of stay

This table is an excerpt from the BADS Directory of Procedures 6th edition. Further detail, including inclusions and exclusions can be found in the original document.

Table 10: Recommended length of stay

Description	Procedure room	Zero night stay	One night stay	Two night stay
Total subtotal thyroidectomy		-	70%	30%
Hemithyroidectomy, lobectomy, partial thyroidectomy		30%	70%	-
Excision of lesion of parathyroids		60%	40%	-

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Appendix 4: Questionnaire for providers

Trust Code	Trust Name
Enter Trust Code	*Enter Trust Name*

Name of Consultant Completing Questionnaire	Department/Specialty

Q1 What type of Endocrine Department are you?

Endocrine Department in a District General Hospital (secondary)	☐
Specialised Endocrine Department in a General Hospital (tertiary)	☐

Q2 What endocrine services do you diagnose and follow up in your service:

Thyroid	
Primary Hypothyroidism	☐
Thyrotoxicosis	☐
Multinodular goitre	☐
Graves' orbitopathy	☐
If Yes - MDT?	☐
Thyroid cancer	☐
Pituitary	
Prolactinoma	☐
Acromegaly	☐
Cushing's disease	☐
Non-functioning tumour	☐
Craniopharyngioma	☐
Diabetes insipidus	☐
Adrenal	
Hyperaldosteronism	☐
Phaeochromocytoma	☐
Addison's disease	☐
Congenital adrenal hyperplasia	☐
Reproductive Endocrinology:-	
Polycystic ovary syndrome	☐
Premature ovarian failure	☐
Menopause	☐
Female infertility	☐
Male hypogonadism	☐
Erectile Dysfunction	☐
Male infertility	☐
Calcium & Bone Metabolism	
Hyperparathyrodism	☐
Hypocalcaemia	☐
Vitamin D deficiency	☐
Osteoporosis	☐
If Yes - Fracture Liaison Service?	☐
Paget's dsiease	☐
Metabolic Bone Disease	☐
Neuroendocrine Tumours:-	
Insulinoma	☐
Inherited endocrine syndromes	☐

Q3 Colocation of services in your Trust: *(tick if colocated)*

Thyroid surgery	☐
Parathyroid surgery	☐
Pituitary Surgery	☐
Adrenal Surgery	☐
Oncology	☐
If Yes - Late Effect Joint Clinics?	☐
Reproductive endocrinology including IVF	☐
Paediatric endocrinology	☐
Genetics	☐
Transitional endocrinology	☐
If Yes - Joint Paediatric Adult Clinics?	☐
Specialised neuroendocrine surgery	☐
Pancreatic surgery	☐
Intensive care	☐
Accident & Emergency	☐

Q4 Personnel:

What is the number of consultant level doctors doing sessions in endocrinology employed in your trust?	
What is the number of doctors providing a majority of endocrinology as opposed to diabetes in their job description?	
What is the number of PAs per week provided by your trust in clinical (clinics/MDTs/meetings) endocrinology?	
What is the number of registrars in your Trust in endocrinology?	
What is the number of full time equivalent PAs per week provided by registrars?	
What number of specialist endocrine nurses is employed by your Trust?	
What is the total WTE of spec. endocrine nurses employed by the Trust?	

Q5 Consultant Out of Hours Arrangements

Do you have a formal system by which it is clear who is responsible for out of hours calls at consultant level in endocrinology? ○Yes ○No

Q6 Outpatients:

What is the number of new outpatients seen per year?	
What is the number of follow-up patients seen per year?	
Of the new outpatients seen per year, how many are specialist endocrine patients (as defined by the endocrine clinical reference group see link below)?	

https://www.england.nhs.uk/commissioning/spec-services/npc-crg/group-a/a03/

Are there facilities for seeing non-malignant urgent new patients (e.g. thyrotoxicosis (if necessary), ?Addison's, ?Phaeochromocytoma) in the clinic within two weeks? ○Yes ○No

Are there sufficient follow up appointments for these patients in the clinic to be seen again with a month? ○Yes ○No

Are there CCG imposed new to follow up ratios in endocrinology? ○Yes ○No

Is there an electronic GP endocrine or telephone advice line? ○Yes ○No

If yes, during what hours is it available?

Hours: Mon -Fri	Hours: Sat/Sun

Is there a dedicated specialist nurse email or phone line for patients? ○Yes ○No

If yes, during what hours is it available?

Hours: Mon -Fri	Hours: Sat/Sun

Does your endocrine dept. organise tests prior to seeing new patients in clinic so that results are available when the patient is first seen as a new patient? ○Yes ○No

Approx what % of new outpatients have such pre-organised tests with results available when the patient is first seen? %

Do you provide telephone appointments? ○Yes ○No

What proportion of your clinic apointments are remote (telephone)?

Do you have or are there plans for regional remote clinics, e.g., by skype? ○Yes ○No

Q7 Adrenal Patients:

How many patients with adrenal incidentalomas are investigated per year?

Is there a fixed protocol for these investigations?
- ○ Yes
- ○ No

How many patients with Addison's disease are there who attend the clinic at least yearly?

Are all patients with adrenal insufficiency given an emergency injection kit by the department?
- ○ Yes
- ○ No

Is there tuition for Addison's patients or relatives in injection use?
- ○ Yes
- ○ No

Q8 Thyroid:

What is the number of new thyrotoxic patients seen per month?

In what proportion of these patients are thyrotropin antibodies measured? %

Is written information provided about agranulocytosis before treatment with ATD's?

Q9 Specialised investigations:

Are there facilities in the hospital for selective adrenal vein venous sampling?
- ○ Yes
- ○ No

If so how many are done per year?

In what proportion is the right adrenal succesfully catheterised (cortisol equal to or greater than 2 versus peripheral) %

Are there facilities in the hospital for inferior petrosal sinus sampling?
- ○ Yes
- ○ No

If so, how many of these are done per year?

Q10 Endocrine Networks:

Which departments do you liaise for (referral or patients referred):

	Trust	Department
Thyroid cancer		

Are there agreed regional protocols for follow up?
- ○ Yes
- ○ No

Pituitary		

Are there regional referral protocols to refer (e.g., suspected Cushing's quickly within two weeks) and to a pituitary surgeon operating on at least 12 to 20 or more cases per year
- ○ Yes
- ○ No

Are there written agreed protocols for follow up?
- ○ Yes
- ○ No

Neuroendocrine tumours		

Are there written agreed protocols for follow up?

○Yes
○No

Adrenal		

Are there regional referral protocols to refer (e.g., 4cm adrenal masses to an adrenal surgeon within two weeks; operating on at least 6-10 or more cases)?

○Yes
○No

Are there written agreed protocols for follow up?

○Yes
○No

What are the numbers referred/received from outside your Trust in a year for:

Thyroid cancer	
Pituitary	
Neuroendocrine tumours	
Adrenal	

In total, how many tertiary referrals (for initial or further diagnosis and/or management) from other secondary providers did you received in the last 12 months?

Q11 MDTs:

Do MDTs as defined by the endocrine spec (see link below) meet regularly (in person or virtual) to discuss these patients?

https://www.england.nhs.uk/commissioning/spec-services/npc-crg/group-a/a03/

Thyroid cancer	○Yes ○No	Number of meetings per year?	
Pituitary	○Yes ○No	Number of meetings per year?	
Neuroendocrine	○Yes ○No	Number of meetings per year?	
Adrenal	○Yes ○No	Number of meetings per year?	

What is the composition of the MDT? Please name specialty and chair for each MDT and other members and specialty

	Details: Please name specialty and chair for each MDT and any other information you consider relevant.
Thyroid cancer	
Pituitary	
Neuroendocrine	
Adrenal	

Q12 Surgery:

What was the number of patients in whom adrenalectomy was carried out in 1/4/16 to 30/3/2018?

What was the number of patients operated on in your Trust for adrenal cancer in 1/4/16 to 30/3/2018

Names of Surgeons undertaking adrenalectomies and cancer adrenalectomies:

Name of Surgeon	Main Surgical Specialty	No. of Adrenalectomies 1/4/16 to 31/3/2018	No. of cancer Adrenalectomies 1/4/16 to 31/3/2018

Surgeons undertaking parathyroidectomies:

Name of Surgeon	Main Surgical Specialty	No. of Parathyroidectomies 1/4/16 to 30/3/2018

What is the failure rate for parathyroid surgery, adenoma not found, for each surgeon:

	1/4/16 to 30/3/17	**1/4/17 to 31/3/18**
Total number of cases in the period		
Total number of cases of parathyroid gland not found		

Surgeons undertaking pituitary surgery

Name of Surgeon	Main Surgical Specialty	No. of Cases, 1/4/16 to 30/3/2018

What is the success rate for surgery for Cushing's (cortisol <50 within three months), each surgeon:

Name of Surgeon	Number of **micro** adenomas in 1/4/16 to 30/3/2018?	Number successful?

Name of Surgeon	Number of **macro** adenomas in 1/4/16 to 30/3/2018?	Number successful?

What is the success rate for surgery for acromegaly within three months (growth hormone < 1ng/ml, IGF1 normal) after somatostatin withdrawal (each surgeon):

Name of Surgeon	Number of micro adenomas in 1/4/16 to 30/3/2018?	Number successful?

Name of Surgeon	Number of **macro** adenomas in 1/4/16 to 30/3/2018?	Number successful?

Thyroid Surgeons Undertaking surgery for Cancer

Name of Surgeon	No. of Cases

Thyroid Surgeons Undertaking surgery for thyroid surgery for endocrine indications

Name of Surgeon	No. of Cases

Are any Surgical data returned to the BAETS database? Yes/No

Q13 Obesity Services

Is there a multidisciplinary obesity service which runs in your hospital: ○Yes ○No

If No, is one planned in the next year? ○Yes ○No

Q14 How many completed audit projects were carried out in 1/4/16 to 30/3/2018?

Q15 Has a patient survey been carried out in the last 12 months?

Has a patient survey been carried out in the last 12 months? ○Yes ○No

If no, is one planned in the next year ○Yes ○No

Q15 What innovation or best practice improvements have been made in the last three years in your department?:

1	
2	

Q16 Do you have any concerns about your service or things you wish to improve?

1	
2	

Please enter the name and main surgical speciality of surgeons conducting…

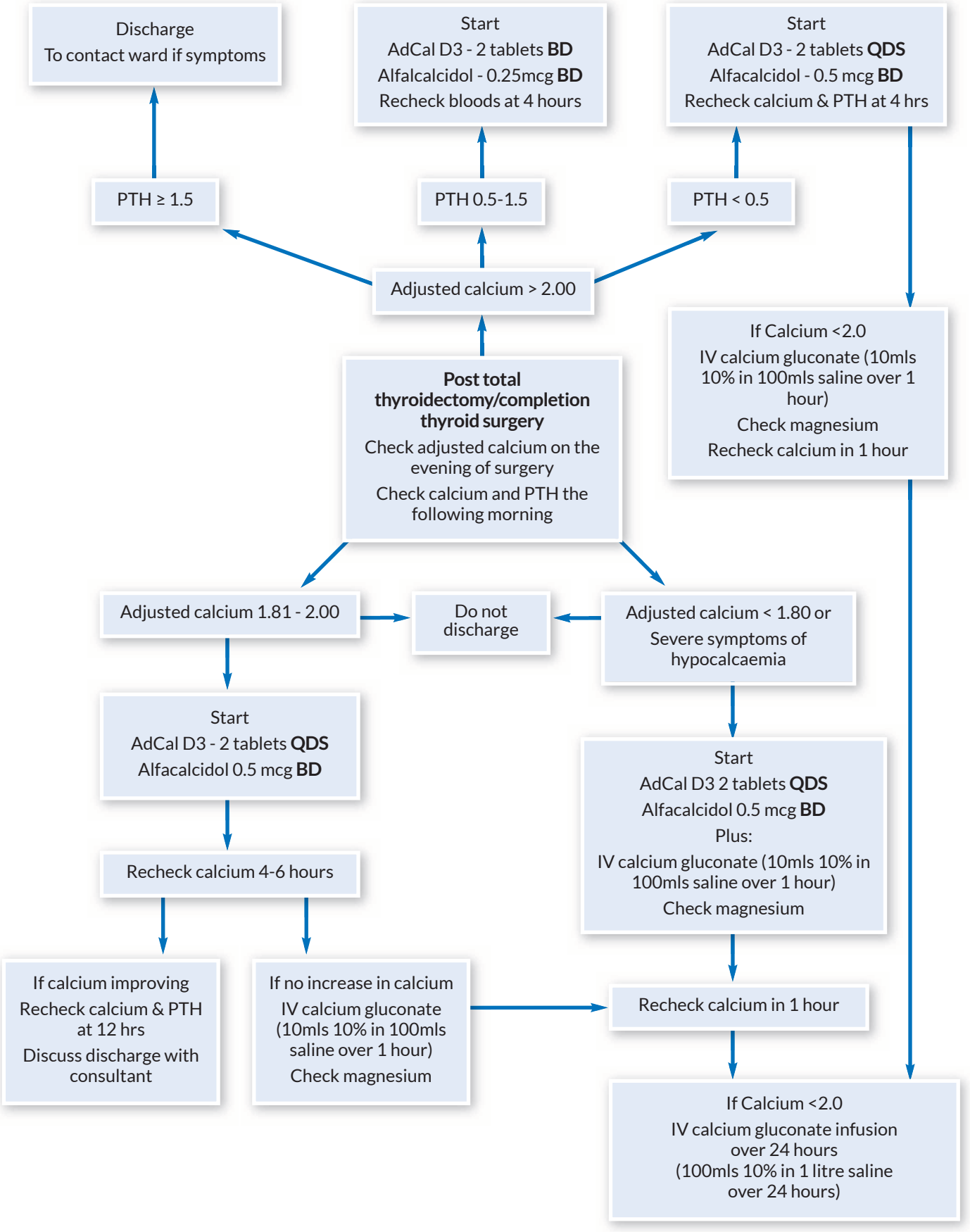
Please add the number of cases for…..conducted between 1/4/16 to 31/3/2018

	Name of Surgeon	Main Surgical Specialty	Unit	All Adrenalectomies	Cancer Adrenalectomies	Phaeocromocytoma	Parathyroidectomies	Thyroid surgery for cancer indications	Thyroid surgery for non- cancer indications	Pituitary surgery for non-functioning pituitary tumours	Pituitary surgery for acromegaly caused by microadenomas	Pituitary surgery for acromegaly caused by macroadenomas	Pituitary surgery for Cushing's disease caused by microadenomas	Pituitary surgery for Cushing's disease caused by macroadenomas
Example	A.N Other	XYZ	XYZ	0	10	0	0				1		2	
Surgeon 1														
Surgeon 2														
Surgeon 3														
Surgeon 4														
Surgeon 5														
Surgeon 6														
Surgeon 7														
Surgeon 8														
Surgeon 9														
Surgeon 10														
Surgeon 11														
Surgeon 12														

	For each surgeon conducting **pituitary surgery**…what is the	A) % success rate between 1/4/16 to 31/3/2018 for	B) % success rate between 1/4/16 to 31/3/2018 for	B) % success rate between 1/4/16 to 31/3/2018 for	C) % success rate between 1/4/16 to 31/3/2018 for Cushing's
Example	A.N Other	N/A	N/A	N/A	N/A
Surgeon 1	0				
Surgeon 2	0				
Surgeon 3	0				
Surgeon 4	0				
Surgeon 5	0				
Surgeon 6	0				
Surgeon 7	0				
Surgeon 8	0				
Surgeon 9	0				
Surgeon 10	0				
Surgeon 11	0				
Surgeon 12	0				

Thank you for taking the time to complete this Survey

Appendix 5: Example flow chart, management of post-operative hypocalcaemia



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