DEFINING THE FUTURE OF ENDOCRINOLOGY

Harnessing innovation and driving change to improve endocrine services and training in the post-COVID NHS

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1 Executive Summary

The COVID-19 pandemic in 2020 presented a unique opportunity to re-assess and define the future of endocrine care and training in this country in the post COVID-19 NHS. The Society for Endocrinology’s Clinical Committee formed a working group of healthcare professionals to review endocrine care and training in the NHS and produce a report recommending changes that would ultimately improve endocrine patient care. The group concluded that:

• Endocrinology services must be transformed to make them more patient centric and safe whilst delivering the highest quality in clinical care and training.
• Endocrine service re-design must seek to reduce inequalities of access or utilisation that currently exists.
• Primary and secondary care should work together to agree management pathways for people with endocrine conditions; and agree rapid Advance and Guidance (A&G) that are timely, supportive, recordable in patient records, and auditable.
• National/regional secondary and tertiary care networks for complex endocrine conditions should be enhanced.
• Patient safety in key areas should be reviewed and enhanced.
• During significant healthcare emergencies, such as the COVID-19 pandemic, the minimum capacity required to provide safe endocrine care is 25%.
• There should be at least one specialist endocrine nurse in each specialist unit.
• Training in endocrinology needs dedicated time that is protected from other activities such as General Internal Medicine.

The recommendations in this document are not intended to be a blueprint or to mandate how endocrine services should be run. Instead, it is intended to be seen as a resource that describes principles and provides advice for service configuration; to act as a toolkit to help with service development; and to signpost examples of good practice that have been developed across the endocrine community. The Society is also working with NHSEI to align their new guidance on endocrinology outpatients with the recommendations in this report.

‘Endocrinology services must be transformed to make them more patient centric and safe whilst delivering the highest quality in clinical care and training.’
‘We have an opportunity to use what we have learnt (through the pandemic) and create endocrine services which place our patients firmly at the centre of what we do.’
The COVID-19 pandemic has had a profound impact on the delivery of healthcare. The pressure to adapt — generated when clinicians and nurse specialists were redeployed to acute care, and patients became anxious about visiting hospitals — led to a rapid transformation in clinics. Face-to-face activity ceased almost completely, telephone and video consultations increased and there was a shift to managing patients virtually, based on investigation results. Changes in these clinical working models demonstrated the potential for improved patient experience, and presented the opportunity to retain models that work well and to transform others where needed.

NHS England sees transformation of clinics to assist recovery from COVID-19 as essential, whilst looking for ways to improve effectiveness and reduce activity which fails to lead to patient benefit. The new integrated care systems (ICS) — in place by 2022 — will be looking to make savings by avoiding duplication of care and unnecessary secondary care activity. Payment by results seems very unlikely to return, and most commissioning will remain in block contracts where acute trusts will be encouraged to manage services within pre-set budgets for the foreseeable future. The ICS approach to integrated care will build on the population medicine approach in NHS England typified by the ‘Right Care’ movement, looking to maximise value in healthcare. While these particular policies are limited to England, the direction of travel is similar across the devolved nations.

The models of care chosen for individual institutions will depend on the IT systems available and relationships with primary care services, geography, population needs, expertise and staffing. Maintaining equity of access for all patients is essential; some are less able to access digital systems, and we do not yet know what ‘good’ truly looks like in the new, hybrid world of working. By co-designing models of care with patients, their support and advocacy groups, and colleagues in the community and primary care, we can develop the best services for local populations and infrastructures.

(S Ball, The Endocrinologist, Autumn 2020).

There are multiple benefits of reviewing how we deliver care for our patients. It enables us to:

• develop a better overview of our patient population
• manage and track high-risk patients more effectively
• reduce unnecessary appointments
• maximise high-value clinical encounters
• manage pressure on staff better
• address administrative issues
• involve patients more in their care
• improve quality.

In addition, the Health Foundation has emphasised four key principles underpinning service restoration and reform:

Understanding and addressing the full extent of unmet need
Reassuring the public about using services
Looking after and growing the workforce
Improving, not just recovering, services.

Endocrinology is predominantly an outpatient specialty and outpatient activity has doubled in the past 10 years. Even prior to the COVID-19 pandemic, the NHS 10-year plan mandated a move to more virtual working. With the expansion in digital healthcare, the creation of integrated care systems and better collaboration with primary care, we now have a range of tools to enable us to work differently. The last 18 months have brought dramatic changes in the way we deliver outpatient care and many have already started the journey towards transforming their services. We have an opportunity to use what we have learnt and create endocrine services which place our patients firmly at the centre of what we do; to deliver specialist patient care to the right person, in the right place, at the right time.
Mission STATEMENT

To address these challenges the Society for Endocrinology created a diverse working group with the following remit:

‘To seize new opportunities to ensure world-class equitable care for patients with endocrine disorders in the UK by harnessing research, education, and new ways of working.’

**The working group’s purpose:**

‘To consider ways of transforming endocrine services to ensure world-class equitable care for patients, whilst meeting the needs of trainees, and recommend how these might best be implemented and sustained within the NHS post-COVID-19.’

**This was to be done by:**

‘Bringing together UK-wide expertise across clinical endocrinology, to define the most effective, future-focused endocrinology service models.’
An extraordinary meeting of the Society’s Council was held on 15 May 2020 to discuss and approve the formation of a new working group, reporting to the Clinical Committee, to consider and report on the opportunities to reshape clinical care in endocrinology across the UK.

An open call was put to the membership asking for specific skills and experience. The final composition of the core working group, which reflects these skillsets together with member and geographical diversity of the Society, was as follows:

- **Kristien Boelaert**, Consultant, Birmingham (Co-Chair)
- **John Newell-Price**, Consultant, Sheffield (Co-Chair)
- **Afroze Abbas**, Consultant, Leeds
- **Antonia Brooke**, Consultant, Exeter
- **Sherwin Criseno**, Consultant Nurse, Birmingham
- **Maralyn Druce**, Consultant, London
- **Helena Gleeson**, Consultant, Birmingham
- **Steven Hunter**, Consultant, Belfast, NI
- **Shazia Hussain**, SpR, London
- **Ashwin Joshi**, Consultant, Sunderland
- **Kate Laycock**, ST5 Registrar, London
- **Christine May**, Consultant, Oxford
- **Karim Meeran**, Consultant, London
- **Douglas Robertson**, Consultant, Mid Cheshire
- **Helen Simpson**, Consultant, London
- **Philip Newland-Jones**, Consultant Pharmacist for Diabetes and Endocrinology, Southampton

Additional members (non-Society for Endocrinology)

- **Clare Hambling**, GP, Norfolk
- **Helen Parretti**, Consultant Clinical Associate Professor, University of East Anglia and GP (representing the Royal College of General Practitioners)

Additional members (Society for Endocrinology)

- **Zoe Plummer**, Research and Professional Practice Manager

A further subset of the applicants with specialist expertise were invited to become affiliated members of the working group:

- **Peter Clayton**, Consultant, Manchester (Paediatric Endocrinology)
- **Waljit Dhillo**, Consultant, London (National Institute for Health Research (NIHR))
- **Fraser Gibb**, Consultant, Edinburgh (endocrinology in Scotland)
- **Neil Gittoes**, Consultant, Birmingham (Clinical Reference Group (CRG))
- **Mark Gurnell**, Consultant, Cambridge (Training and Education)
- **Dinesh Nagi**, Consultant, Yorkshire (Association of British Clinical Diabetologists)
- **Aled Rees**, Consultant, Cardiff (endocrinology in Wales)
- **John Wass**, Consultant, Oxford (Getting It Right First Time (GIRFT))
- **Peter Winocour**, Consultant, Hertfordshire (Royal College of Physicians)

The remainder of applicants were asked to act as initial consultants as the work of the group progressed.

The Society’s Clinical and Nurse Committees have informed, reviewed and approved the content of this document.

‘Bringing together UK Wide expertise across clinical endocrinology, to define the most effective, future-focused endocrinology service models.’
The initial work was to gain insight into the landscape of current endocrine care, where and how this may be changed and improved, what examples there were of innovative practice, and how recommendations could be framed within healthcare structures. To do this we surveyed Society-affiliated patient support groups (PSGs) and existing endocrine services (crowdsourcing of novel working by an open call for examples), and used resources already available to the Society including:

- GIRFT report
- Society for Endocrinology peer review findings
- already available, external, online resources
- shared pathways and protocols.

This document is not intended to be a blueprint or to mandate how endocrine services should be run. Instead, it is intended to be seen as a resource that describes principles and provides advice for service configuration; to act as a toolkit to help with service development; and to signpost examples of good practice that have been developed across the endocrine community.

The Society for Endocrinology will house these outputs within the Members’ Area of the website in a new Resource Hub (SfE Resource Hub – link to follow).
6 Recommendations

Endocrine services must be transformed to be more patient-centred and safe, whilst delivering the highest quality in clinical care and training. The delivery of care requires enhanced working with acknowledged patient support groups, and closer integrated working between primary and secondary care. New models of care include virtual and remote consultations. The Society has developed a portal with resources to help address these needs. Owner: all endocrine service providers, Society for Endocrinology, CRG, GIRFT

Endocrine service re-design must seek to reduce any inequalities of access or utilisation that currently exist. Endocrine services and models of care must allow patients to be managed flexibly depending on their needs. Services will need combinations of patient/healthcare worker interfaces including: face-to-face, virtual, patient portals, and patient-initiated follow-up. Owner: all endocrine service providers, Society for Endocrinology, CRG, GIRFT

Patient safety in key areas should be reviewed and enhanced. Patient safety during pre-hospital care, inpatient stays and post-discharge/follow-up should be considered for the following key areas: steroids in adrenal insufficiency, hypo- and hypercalcaemia, hyponatraemia, diabetes insipidus, pituitary apoplexy and thyrotoxicosis. Owner: all endocrine service providers, Society for Endocrinology, RCP, CRG, GIRFT

During COVID-19 waves or other pandemics, the minimum capacity we deem to provide safe endocrine patient care is 25%. Speciality training for endocrine trainees should be maintained. Primary, secondary and tertiary care working should be integrated as much as possible with shared systems. Patients for whom virtual consultations are appropriate long term should be identified. Phlebotomy services, multidisciplinary teams (MDTs) and workload priorities should be reviewed against available resources. The Society has developed an online COVID resource, revised by this working group, which will allow members to share both the recommendations in this report and other best practice with their peers. Owner: all endocrine service providers, Society for Endocrinology, RCP SAC, Deaneries

Primary and secondary care in a given locality should agree rapidly available ‘Specialist Advice’ (including Advice and Guidance (A&G) and Referral Assessment System) that is timely, supportive, recordable in patient records and auditable. Local systems may already be in place, but if not it is recommended that they be made available, and appropriately resourced. Secondary care should use a Referral Assessment System rather than directly bookable clinic appointments and make use of ‘straight to test’ options, as well as responding to a referral as augmented A&G, following results of investigations performed in secondary care. Owner: all endocrine service providers, GIRFT, Society for Endocrinology (peer review)

Primary care and secondary care in a given locality should agree management pathways for people with endocrine conditions. Secondary care needs to offer training and support to primary care clinicians looking after that population. Primary care testing for common endocrine conditions and pathways for life-threatening endocrine conditions, as identified by the GIRFT report, are addressed in this report and are recommended as blueprints upon which service provision can be modelled. These testing pathways need to be appropriately commissioned and any changes to pathway/testing requirements need to be agreed locally with primary and secondary care clinicians and commissioners. Owner: all endocrine service providers, Society for Endocrinology, RCPG, CRG

Patients should receive detailed information on their condition and the treatment options available, and have reassurance of absence of significant pathology where appropriate. Letters written from secondary care directly to a patient with advice and actions for GP are a powerful tool to engage patients in their care. Specific letters of advice and action to the GP may also be needed. Owner: all endocrine service providers, patient support groups

Discharge from endocrine clinics should give clarity about follow-up. Specific and SMART management plans are needed on discharge, including when to re-refer, together with written/documentated information between all parties. Ready access to advice and discussion following discharge should be in place in a given locality. Owner: all endocrine service providers, Society for Endocrinology (peer review)

Regional/national - secondary/tertiary care networks for complex endocrine conditions should be enhanced. Agreed pathways and signposting of care to allow rapid and appropriate passage of patients along pathways of care need improvement for some endocrine conditions including pituitary, adrenal and complex bone. An example of where this is well established is for neuroendocrine tumours (now termed neuroendocrine neoplasms), and the ENETS Centres of Excellence model could be used for other endocrine conditions. Owner: all endocrine service providers, Society for Endocrinology, CRG
Regions need to work together to enhance outcomes for complex endocrine investigations including venous sampling. Higher volumes of diagnostic interventions such as adrenal and inferior petrosal sinus sampling are associated with better performance of these tests. Expertise for such testing is needed at regional rather than centre level to enhance outcomes. Owner: all endocrine service providers, Society for Endocrinology, CRG

Endocrine Investigation Units need appropriate resource, space and training. Dedicated resourced and staffed areas are needed for complex endocrine investigations, with regions working together for smarter use of existing resource. These units should be staffed by an experienced team, competent to undertake the tests (e.g. as defined in the Society for Endocrinology Competency Framework for Adult Endocrine Nursing). Owner: all endocrine service providers, Society for Endocrinology (peer review), GIRFT

Endocrine Nursing. In line with the GIRFT report, we support the recommendation that there should be at least one Endocrine Specialist Nurse (ESN) in each endocrine centre, more in the larger and busier centres, with a 12-month review of service provision encouraging growth, appropriate cover and succession planning. The role of the ESN in inpatient endocrine care should be further explored and developed to support inpatient endocrine services. A support plan should be written to enable endocrine nurses to complete the Society for Endocrinology Competency Framework for Adult Endocrine Nursing and they should have the opportunity to attend appropriate academic and professional meetings, network, observe peers and progress their career (e.g. Oxford Brookes University Masters-level module in Endocrine Nursing). ESNs should support and train healthcare assistants and nurse associates working in the field of endocrinology. Owner: all endocrine service providers, Society for Endocrinology, GIRFT

Endocrine helplines/phone access for patients to ESNs are needed for all patients. These are provided by many patient groups but may need enhancement at provider level, and nurse and administration time needs to be costed in to ensure that these function well. Owner: all endocrine service providers

Job planning and training needs to take account of service re-design and new models of working. With pressures on service recovery and transforming to a four-year registrar training programme there is an opportunity to design world-leading endocrinology training, enhancing its recruitment and future strength. To achieve this needs time and resource for clinicians, trainees and trainers. Owner: all endocrine service providers, Society for Endocrinology, RCP

Training in endocrinology needs dedicated time that is protected from other activities such as General Internal Medicine. Similar to experience in other specialities trainees must have sufficient time to gain the wide experience needed in a range of specialised clinics, and to do this the time in training needs to be protected. For this to occur there needs to be discussions between the RCP SAC, Deaneries and Trusts to ensure that the quality of training is not diminished and indeed enhanced, and that all training programs afford the necessary quality of training. The quality of training in endocrinology can be to be improved by use of pre- and post-clinic meetings, adjusted to suit the trainee and stage of training. Owner: all endocrine service providers, Society for Endocrinology, RCP SAC, Deaneries

Training in endocrinology can be enhanced through existing MDTs and simulated learning experiences. National and regional MDTs in areas of super-specialist interest should be used as training opportunities, with trainees attending as guests. This is already happening in thyroid cancer, and opportunities exist to do the same in neuroendocrine tumours, complex pituitary, adrenal and bone. Options include regular national MDTs or a rotating ‘open’ MDT in different centres to enhance training opportunities. Owner: Society for Endocrinology, RCP SAC, CRG

The Society should develop an enhanced training support hub. This should include: patient experience videos of care and pathway, ‘model’ clinic encounters of frequently encountered endocrine conditions and simulated clinic encounters. A one-stop shop of training opportunities should be developed and curated. Owner: Society for Endocrinology

Research needs to be better embedded in day-to-day endocrine care. The Society needs to work with other national bodies to enhance access to clinical research for patients — to promote research as ‘core business’ for clinical endocrinology. Patient involvement in discussions, through clinical consultations and in setting research priorities within endocrinology, would assist in this endeavour. Opening conversations beyond those who may voice an interest in research involvement will be important. Owner: Society for Endocrinology, NIHR, CRG
To ensure the working group was fully informed by the patient voice, the first activity in August 2020 was a survey of all Society-affiliated patient support groups (PSGs). This exercise gave valuable insight into the models of care that would best serve their communities and what a ‘good’ service would look like to them. Many of the PSGs consulted with their patient representatives and some were able to share patient experience survey data collected both prior to and during the pandemic. The key consensus feedback is summarised below.

**ACCESS AND COMMUNICATION**

Endocrinology helplines (provided by patient advocacy groups, doctors, nurses and multidisciplinary teams) are considered an invaluable source of support and information for both GPs and patients. However, many patients feel GPs lack clear referral criteria and that this is a big barrier to achieving the right care in the right place at the right time.

When reaching secondary care, many patient groups report that patients would prefer a face-to-face appointment but support the use of digital options (including video, telephone and virtual clinics) thereafter where possible, clinically appropriate and depending on patient preferences. Time off work, parking and cost of travel were frequently cited as reasons to prefer virtual appointments. Patients prefer local delivery of pre-clinic blood tests and investigations, where feasible, with blood test templates provided for GP use. Where investigations are done alongside the clinic, patients request that they are contacted with results.

Pre-clinic questionnaires were suggested to help to establish objectives for secondary care consultations. Patients said they would appreciate direct contact with endocrinology secretaries when arranging initial appointments and with an endocrine nurse specialist thereafter.

Patients favour multidisciplinary clinics (e.g. joint pituitary) and subspecialist care models (hub and spoke) where appropriate, but worry that being seen by multiple clinicians results in a lack of continuity of care. The provision of a named Clinical Nurse Specialist (CNS) or patient navigator was suggested to alleviate these concerns.

Patients are keen to be involved in their care and would value a more patient-centred approach and improved shared decision making. The use of patient-initiated follow-ups would work well for some patients and PSGs reported that the use of expert patient programmes that nurture patients to assist and encourage self-management would be of benefit to both patients and the healthcare system.

Patients support the development of patient portals and a patient held record allowing them to view results and letters. They would welcome further opportunities for two-way digital communication with care providers to include the wider use of email correspondence with medical teams and secretaries. Patients would also welcome e-prescribing so that changes to medication can be implemented immediately. Easily accessible, up-to-date medication lists (those dispensed) would also be appreciated.

‘The working group was fully informed by the patient voice.’
EDUCATION AND TRAINING

Patients report a need for improved education and training for non-endocrine specialists such as GPs and medical/nursing students, to improve management of long-term complex endocrine patients and raise awareness of physical and mental symptoms of endocrine disease. There is a need for improved endocrinology-specific psychological services, particularly for conditions affecting children and transition services: a suspected difference or disorder of sex development (DSD), Klinefelter syndrome (KS), Turner syndrome (TS) and congenital adrenal hyperplasia (CAH). PSGs and patients are happy to support education and training and patients are keen to participate in medical and higher training examinations.

All patients should be provided with written information about their condition and should be signposted to reputable online information and PSGs. The provision of emergency and pre-hospital service information could be improved and group education for endocrine conditions was suggested as a useful development.

SAFETY

Patient safety is unsurprisingly high on the agenda, with PSGs feeling more can be done to protect patients. Patients recognise there is inconsistency in care nationally and — though delighted with the NHS Steroid Emergency Card, for example — wider use of red-flagging in the notes or electronic patient record would help minimise risk and standardise care.

There is a need for generic letters for emergency presentations and the wider use of emergency care plans. Patient-led blood testing (via provision of a spare form) is valued.

RESEARCH

Patients are generally supportive and keen to get involved with research and PSGs are already helping to facilitate this. Two support groups requested national patient registers that could be used for audit, coding and research purposes. Capturing the views of patients themselves in this area remains an important goal.
To address the issues raised by the PSGs and to provide proposed solutions, the working group considered the following key areas:

• COVID-19 — future waves/pandemics
• innovation, change and service transformation:
  • utilising PSGs
  • patient safety
• transformation of endocrine services and models of care
• closer and integrated working between primary and secondary care
• training in endocrinology in the new models of care.

In doing this, the working group was highly cognisant of the framework of the existing and developing NHS, NHS priorities, the GIRFT report, the CRG for Specialised Endocrinology, the challenges facing primary and secondary care physicians, the feedback from numerous colleagues across the country who had provided examples of innovative successful practices, and learnings gleaned from the Society peer review scheme. In addition, five key principles were kept at the forefront of discussions: equity of access, quality and safety, communication, teaching and training, and research.
Resources for future COVID-19 waves or other pandemics

Given the status of the pandemic at the time the project was instigated, with the first wave of COVID-19 over and the second wave expected in the autumn of 2020, this area of work was given precedence. All existing resources were assessed and revised in light of learnings from the first wave, and new resources developed as needed. These, together with summary advice, were published on the Society’s website in October 2020 ahead of the second wave.

The key recommendations were:

• During COVID-19 waves or other pandemics, the minimum capacity we deem to provide safe endocrine patient care is 25%. Capacity should be kept higher wherever possible.

• Roles for specific team members, including nurses, shielding colleagues and registrars should be clearly defined.

• Speciality training for endocrine trainees and nurses should be maintained.

• Primary, secondary and tertiary care working should be integrated as much as possible with shared systems.

• Primary, secondary and tertiary care centres within a region should understand referral routes for patients.

• Patients for whom virtual consultations are appropriate long term should be identified.

• Phlebotomy services, MDTs and workload priorities should be reviewed against available resources.
Innovation, change and SERVICE TRANSFORMATION

Endocrine services should meet the needs of patients whilst working within the framework of the current NHS. Having surveyed the PSGs, we then considered how best to align services to their needs. Here we offer suggestions and solutions that allow service transformation, whilst still ensuring that the needs of the training workforce are met. General recommendations around service transformation are available from The Health Foundation.

10.1 PATIENT SUPPORT GROUPS (PSGs)

The Society for Endocrinology works with 20 affiliated PSGs, each with a specific endocrine remit. Clinicians are not always aware of PSGs or the breadth of services they offer. This is particularly true for clinicians in the early stages of their career. PSGs offer peer support for patients with endocrine conditions, many of which are also classed as rare conditions. Working with PSGs allows healthcare professionals (HCPs) to inform and support their patients, giving them access to more extensive information. Many PSGs have medical trustees or a clinical panel and co-design patient information. This was particularly fruitful during the COVID-19 pandemic, where many PSGs worked with their medical advisors to produce information to keep patients safe. Examples include the Addison’s Disease Self-Help Group (ADSHG) sick day rule changes for COVID-19 and information about COVID-19 vaccines for those managing adrenal insufficiency.

To enable HCPs to connect their patients with relevant PSGs and enhance the support they are offered, the following information will be made available on the Society website:

- links to each affiliated PSG’s website
- an outline of what each PSG provides
- safety alerts and guidance
- helpline details (if available)
- links to social media accounts.

PSGs communicate widely with their communities. They often have a presence on social media platforms such as Twitter, YouTube, Facebook and Instagram. This extends their reach to a wider audience. Many PSGs host Q&A sessions, linking their members up with HCPs. Some also develop and host educational videos as well as sharing a wide range of resources. For example, each year PSGs send out thousands of leaflets, booklets, videos and alert cards, free of charge to hospitals. Some resources are translated into languages other than English. Throughout the pandemic some patient groups have also hosted regular educational webinars for patients and primary care specialists. PSGs and the local support groups highly value peer and professional group educational events.
10.2 PATIENT SAFETY

Patient safety is essential, and this was highlighted as one of the main PSG priorities. The NHS patient safety strategy is about maximising on areas that work well and minimising areas with more challenges. This strategy was recently updated by NHS England to reflect the disruption and uncertainties arising from the pandemic. This refresh aims to translate safety culture and safety system strands of the strategy into more tangible deliverables.

Patient safety during pre-hospital care, inpatient stays and post-discharge/follow-up should be considered for each of the following key areas:

• steroids in adrenal insufficiency (see example below)
• calcium in hypo- and hypercalcaemia
• sodium in hyponatraemia
• diabetes insipidus
• pituitary apoplexy
• thyroid.

Example: adrenal insufficiency

One important patient safety issue is adrenal insufficiency (AI). In 2020 the Society for Endocrinology, the RCP Patient Safety Committee and NHS England’s Patient Safety team along with others including GPs, the Royal Pharmaceutical College and the Royal College of Clinical Pharmacology, worked together to develop the NHS Steroid Emergency Card and guidance and issued a National Patient Safety Alert which all NHS organisations now have a legal obligation to implement. The Society has a webpage with all of the information, to which the QR code on the NHS Steroid Emergency Card links.

Examples for the other key areas will be made available in the Society’s Resource Hub (SfE Resource Hub – link to follow). Clinical guidelines can be found on the Society website.

10.3 ENDOCRINE SERVICES AND MODELS OF CARE

Prior to the COVID-19 pandemic there was an NHS England (NHSE) plan to reduce the number of face-to-face outpatient appointments by a third, as these appointments have doubled over the last 10 years. The Scottish Government is also aligned to this goal. The RCP developed a sustainable outpatient strategy to re-evaluate the purpose of outpatient care and align those objectives with modern-day living and expectations. The RCP make key recommendations and highlight a need for flexibility from NHS trusts, increased patient control of care and use of available technology. The Scottish Government is aligned to NHSE’s goal of reducing outpatient encounters (https://www.gov.scot/publications/modern-outpatient-collaborative-approach-2017-2020/pages/2/).

Since the onset of the COVID-19, more than 50% of endocrine outpatient clinics have been delivered remotely. Telephone clinics and working with online platforms such as Microsoft Teams for MDT meetings are now the norm. Currently, we face the challenges of further COVID-19 waves coupled with the recovery of delayed activity and waiting lists, whilst maintaining usual services with an already exhausted workforce. Whilst referrals to secondary care fell during the pandemic, they are now back up to pre-pandemic levels.
Figure 2 summarises some of the models of care. Using these, patients can be managed flexibly depending on their needs. There is no doubt that these different ways of working take time to do well. It is therefore important to ensure these are incorporated into job plans and time is allocated accordingly. Working differently also needs support from administration teams (H Wilson, The Endocrinologist, Winter 2020). This means working with managers and others within local services to develop structures to deliver care differently.

**Figure 2: Models of care**

- **Face to Face**
  - Nurse led
  - Doctor lead
  - MDT clinics

- **Virtual**
  - Telephone
  - Video
  - Email/digital

- **Patient portals**
  - Fully integrated EPR
  - Text
  - Email

- **Primary Care interface**
  - Advice and Guidance
  - Stream lining referrals
  - Long term follow up / virtual MDTs

- **Patient Initiated Follow up**
  - Patient takes responsibility for arranging appt date

10.3.1 Face-to-face

In some trusts it may be possible to successfully deliver virtual appointments in endocrinology above the 30% figure stipulated by the NHS Long Term Plan. Nevertheless, face-to-face clinics are usually needed in the following situations:

- most new patient appointments
- when examination is necessary
- when difficult diagnoses need to be explained or decisions need to be made with patients
- due to patient choice or communication difficulties (e.g. due to language or technology barriers)
- to perform endocrine dynamic function tests and give injection training e.g. IM hydrocortisone.

10.3.2 Virtual

The challenge is to establish a new balance between remote and physical consulting, and decide together with our patients which method suits them best. Equity of access needs to be considered (see Figure 3) and patients may need support to use digital tools.

Advantages of virtual clinics include:

- improved access, convenience, choice and flexibility for patients
- reduced need for transport
- saving patients’ time and money
- reduced NHS carbon footprint.

Many organisations have assessed the patient experience of virtual clinics. Office for National Statistics data from August 2020 reported that 68% of patients said they would be comfortable with a virtual clinic appointment.

The Royal National Orthopaedic Hospital found that over 80% of patients were happy with virtual clinics during the peak of the pandemic, whilst it suggested fewer than 50% would like virtual appointments outside of pandemic times.

The Health Foundation also surveyed patient and HCP satisfaction of digital ways of working during the pandemic, in October 2020.

One solution may be to support patients to increase their digital skills and instruct them on how to use the tools required and ensure they have full access. Several organisations are currently developing networks to do exactly this, an example being UCLH Tech Buddies, which developed a system to link up patients with support for using video clinics.

An overall summary of how to set up and perform remote consultations has been provided by a NICE appraisal.

**Figure 3: Considerations for equity for virtual appointments**

- Happiness
- Access to the right tech
- Safeguarding
- Distressing information
- Mental capacity
- Examination and assessments
- Learning Disability or Autism
- Sensory impairments or physical disabilities
- Living with frailty
- Child or young person
10.3.3 Patient portals

Online patient portals allow patients direct access to their healthcare records, letters, results, as well as to send messages to their healthcare team and upload information such as blood sugar levels or blood pressure readings for remote monitoring. With the use of questionnaires, it is possible to determine which patients would benefit from a face-to-face clinic and who could be managed remotely. For example, the UCLH Inflammatory Bowel Service stratifies those needing a face-to-face vs delayed or virtual appointments using questionnaires and blood results on a patient portal. Similar strategies could be developed for endocrine conditions, for example the endocrine patients attending the endocrine services at Birmingham Health Care Partners have direct access to their endocrine biochemistry. If instigating patient portals, careful consideration is needed as to the range of access allowed to ensure information is communicated appropriately. For instance, to avoid access to radiology reports that make new cancer diagnoses apparent, before the patient has spoken to or seen their doctor.

Case study: UCLH Epic Mycare

Three-quarters of patients at UCLH have signed up to the Mycare patient portal. Pre-pandemic patient satisfaction in using a primary care patient portal was high, at 70%, although it was mainly used for prescriptions and booking appointments, rather than messaging about medical care.

During the pandemic lockdowns it was possible to manage some patients remotely. For example, a patient with phaeochromocytoma, who was diagnosed just prior to the first lockdown and started on phenoxybenzamine. Their surgery was delayed for four months but weekly home blood pressure measurements were uploaded to the EPR patient portal, enabling the phenoxybenzamine to be titrated by digital messaging twice a week, with telephone appointments offered every 2–4 weeks until levels were stable.

10.3.4 Patient initiated follow up (PIFU)

There are many endocrine conditions that can be well managed by PIFU. However, this is both condition and patient dependent and requires an individualised approach (https://www.england.nhs.uk/outpatient-transformation-programme/patient-initiated-follow-up-giving-patients-greater-control-over-their-hospital-follow-up-care/). With careful liaison with primary care and the appropriate ease of access for patients, there may be quite a number of patients traditionally followed in secondary care that could be managed by PIFU. For instance, patients cured and stable from pituitary disease, such as an individual with acromegaly cured for the last 10 years. Or a very well-informed patient with stable Addison’s disease, who has been crisis-free for 10 years and is on stable and optimum endocrine replacement therapy. In each case it is important there are appropriate safety nets in place for patients (https://future.nhs.uk/OutpatientTransformation/view?objectid=87035525).

10.3.5 Resourcing

Secondary care job planning

It is important that all new ways of working need effective job planning and agreed resource. There are several guidance documents available to help with job planning including:

• RCP Developing physicians, Diabetes and Endocrinology: workforce and job planning with job descriptions, job plans and person specifications and a checklist for the approval of NHS consultant posts.
• NHS Employers, Consultant job planning (December 2016)
• NHS Employers, A guide to consultant job planning
• Endocrine nurse job plans (SfE Resource Hub – link to follow).

Some organisations are working towards changing their systems for recording consultant activity (e.g. UCLH and their electronic system: SARD). Others, such as Oxford and Sheffield, have already allocated PAs for referral triage and queries. Job plans will need to change as models of care change, and this needs local agreement and implantation.

Primary care

Depending on local arrangement and agreements alterations in resourcing for primary care is likely to be needed.

10.3.6 Endocrine day case units

An endocrine day case unit is safe and effective when it is operated as a self-contained unit that is functionally and structurally separate from inpatient wards. The endocrine day case unit should be managed by endocrine specialist nurses with support from medical staff, healthcare assistants and nurse associates as appropriate. Standard operating procedures should be in place, utilising approved clinical guidelines and protocols relevant to endocrine testing with oversight by the local Trust endocrine quality improvement and patient safety group. See Appendix A for essential components of an endocrine day case unit.

10.3.7 Equity in healthcare

Equity is the absence of avoidable or remediable differences among groups of people, whether those groups are defined socially, economically, demographically, or geographically. The COVID-19 pandemic has highlighted inequities in healthcare (Build back fairer: The COVID-19 Marmot Review, Institute of Health Equity, 2020). However, this was also described by Black in the 1980s, illustrating that inequity in healthcare was increasing even before the COVID-19 pandemic. (The Marmot Review, 10 Years On, Institute of Health Equity, 2020)
It is essential that endocrine service re-design does not create more inequalities, and seeks to reduce any that currently exist. The Kings Fund has provided a summary of the evidence for the use of emerging technologies in care settings, and the Institute for Health Improvement have guidance on improving health equity. Specific examples include interactions with patients who may be disadvantaged in the virtual environment and these include, but are not limited to those with hearing difficulties, those for whom English is not their first language, and those who are not comfortable with virtual format interactions.

NHS England and NHS Improvement provide an Equality and Health Inequalities Impact Assessment template, that can assist clinical services in making an assessment of equity of access.

10.3.8 Service model and patient pathway exemplars in endocrinology

Using the principles outlined above, in Appendix B we describe two services in detail. A primary hyperparathyroidism pathway, as developed at Leeds Teaching Hospitals NHS Trust, and the thyrotoxicosis service from Queen Elizabeth Hospital, Birmingham.

These examples demonstrate different and hybrid ways of working. Each illustrates the process of referral, triage, clinics, outcome and the use of a CNS to deliver services, a mix of face-to-face, telephone and virtual clinics, work shared between the hospital and community, and the interplay between different specialities. These examples are intended to facilitate thought and discussion and to encourage service review and evaluation of similar services in other centres. These examples can be adapted for other endocrine conditions, with changes focusing on improving patient-centered care.

10.3.9 Secondary/tertiary care networks for endocrine conditions

Many endocrine conditions need specialist input, expertise, interventions, surgery and treatments that are available only in larger regional centres. Patients ask for, and are best served by being afforded access to, such expertise early in their diagnostic pathway to avoid delays and repeated investigations. Examples include patients with pituitary disease, adrenal disease, complex metabolic bone disease and neuroendocrine tumours. Regions, and the new Integrated Care Systems, will need to work together to ensure that pathways for referral into the service are clear and efficient, that two-way communication is enhanced, and that outcomes are audited. The virtual MDTs, now widely set up, facilitate regional working in a way that was less well developed before the COVID-19 pandemic. An exemplar of the regional hub and spoke model where such arrangements are highly developed are the European Neuroendocrine Tumour Society (ENETS) Centres of Excellence, with 13 such centres in the UK in 2021. Each centre must demonstrate regional working, have a working database for all patients, provide an annual return of outcome data and are subjected to intense scrutiny during onsite external audits. These centres can serve as a model for service configurations for other endocrine conditions.

Some complex interventions, such as adrenal vein sampling and bilateral inferior petrosal sinus sampling need sufficient ongoing volume to allow the expertise that affords better outcomes, and regions will need to work together to open pathways to allow patients to gain appropriate access. It is highly likely that not all procedures can or should be offered at every large centre, and some may need to be offered on a supra-regional basis. This is highlighted in the GIRFT report. The same holds true for surgical interventions, including those for pituitary disease, adrenal disease (especially for adrenocortical cancer), thyroid cancer, and complex parathyroid disease. Training in some key areas is needed for all endocrinologists regardless of where they work, to ensure that there is sufficient knowledge to appropriately manage and cascade patient care. Training in genetic testing in endocrine disease is a key example.

10.4 PRIMARY-SECONDARY CARE INTERFACE

Even before the COVID-19 pandemic, secondary care endocrine services did not always serve patients well. Most have no measure of the population with a disease in their locality, focusing only on the patients referred to them. Despite this, the GIRFT review often noted services with long waiting times both for new patients and follow-up visits, with the potential for clinical deterioration of patients as a result.

Factors which led to this included ‘payment by results’ which encouraged increased clinical activity to increase hospital income, and ‘choose and book’ which encouraged automatic face-to-face appointments as part of a patient choice agenda, even when they may not be clinically necessary. As funding restraints took hold, to avoid unnecessary costs, some clinical commissioning groups (CCGs) made blanket restriction of referrals to secondary care, at times without discussion with secondary care clinicians.

There was also a lack of clarity about what should be done in secondary care clinics and what could be appropriately left to primary care. This potentially resulted in patients remaining unnecessarily under secondary care follow-up and exacerbating delays in clinic waiting times. As a result, NHS constitutional standard access targets were often breached, causing frustration between CCGs and trusts. To overcome this, clinics were consequently often taking place in overbooked sessions, which resulted in poor patient experience, clinician dissatisfaction, clinician stress and risk of burnout. Referrals between secondary and tertiary care for uncommon or challenging endocrine conditions were often haphazard and fragmented, so patients were kept in secondary care clinics under follow-up to reduce the risk of being lost to follow-up, again exacerbating clinic congestion.

More controversially, these clinician anxieties around ‘case-holding’ might be relayed to the patients, promoting a bilateral culture of dependency between physician and patient, manifest by an unwillingness to discharge and a tendency of the specialist to occasionally take on some of the role of the patient’s GP. Pre-pandemic, NHS England
had started to discuss methods of making referrals more efficient and encouraging changes in follow-up and ‘left-shift’ of care, with more routine follow-up care closer to home in primary or community care.

To inform the working group, endocrine centres were asked to describe how they dealt with the pressures during and after the COVID-19 pandemic, and what innovations that generated. Those particularly relevant to the interface between primary and secondary care have been summarised in Appendix C.

### 10.4.1 Population medicine for endocrine conditions

CCGs have a responsibility to the health of their populations, and this will become more relevant for the integrated care systems (ICS) that will replace them, dealing with increasing demand and constrained resources. For clinical conditions, the concept of population medicine comes to the fore, acknowledging that the best value in managing a disorder may lie in prevention, screening, encouraging self-care, with monitoring in primary care, rather than by referral into a secondary care clinic.

This is not a new approach. Secondary care clinicians have for some time been encouraged to look beyond those patients referred to them to develop population registers, clinical pathways, provide education to primary care and engage with local professional networks and patient groups. This is commonplace in chronic disease management, such as in type 2 diabetes, but scope exists to make use of this model for other common endocrine conditions.

Despite endocrinology’s image as a niche specialty, the common non-diabetic endocrine conditions (e.g. thyroid disorders, hyperparathyroidism, polycystic ovarian syndrome, male hypogonadism, severe obesity) together affect at least 25% of the adult population. Additionally, endocrine testing and interpretation may be needed to exclude endocrine involvement in common conditions such as hypertension or adrenal adenomas or as a cause of extremely common symptoms, such as fatigue, loss of libido or irregular menses.

The development of a local ICS gives an opportunity for secondary care endocrinologists, primary care and commissioners to collaborate to practice population medicine for common endocrine conditions in their locality. This extends to stewardship of the resources available (clinical time, budgets, access to investigations) to manage the condition for the whole population affected.

### 10.4.2 Interactions between patient, primary care and secondary care

The main points of interface between patient, primary and secondary care currently focus on referral, discharge and communication of concerns and results.

GP have traditionally considered an appropriate range of diagnoses but may not have access to the investigations or clinical experience to assess the likelihood of a given endocrine diagnosis. Access to unfiltered internet searches can raise patient anxieties. Previous direct booking systems (direct booking systems through eRS, also previously termed ‘choose and book’) may have raised patient expectations of unrealistic outcome and, at the same time, the delay of many weeks seen in secondary care can lead to frustration, spontaneous resolution or significant worsening of the clinical complaint.

The skill in endocrinology is often to give interpretation of tests which require an understanding of sometimes complex pathways, reassure, recognise occasionally subtle clinical syndromes and to advise on a management plan.

### 10.4.3 Clinic and primary/secondary pathway transformation — overview

The goal of clinic transformation for the future is to improve the patient experience, reduce referral delay and decrease overall workload and costs within the health economy. However, any change will need to provide specific benefits to each party (patient, GP, secondary care clinician) and appropriate resourcing to support changes as well as reduction in overall utilisation and costs to the healthcare system. Joint primary/secondary care records will facilitate patient care, and exist in many localities for diabetes care.

**Benefits for the patient:**

- more timely advice and consultations
- fewer visits to hospital requiring less time and cost for the patient
- less stress and difficulty for those with anxieties around attending hospital or leaving home, and for those with disabilities that make attending hospital challenging
- less inconvenience and cost through less duplication of investigations
- clear communication of reassurance or a management plan for patients in the majority of cases
- prompt treatment or onward referral if needed
- being seen more quickly from time of referral, as secondary care clinics can be more responsive.

**Benefits for the GP:**

- more timely advice or consultation for their patient
- reassurance/validation of their action or a clear management plan if different
- prompt treatment without concern about delay
- avoidance of inadequately resourced additional workload
- improved communication with secondary care
- opportunity to engage in more meaningful conversations • about endocrine conditions
- reduction in patients presenting/contacting surgery due to concerns around delay in being seen in secondary care
- support in managing patients while they are awaiting secondary care consultation.
**Benefits for secondary care clinician:**
- Patient expectations better managed
- Less backlog of new and follow-up patients with less pressure
- Less clinical risk in delayed diagnosis and treatment
- Less overbooked, stressful face-to-face clinics
- Fewer complaints arising from poor patient experience
- Permission to manage clinic activity with less fear of managerial criticism
- Ability to have time to be a genuine contributor to population health in your specialty by having time to educate, support and discuss with primary care.

**10.4.4 Advice, guidance and referrals (see Figures 4 and 5)**

**Specialist Advice**
Frequently a GP may need to discuss cases of diagnostic uncertainty or gain validation for a plan of action and will specifically ask secondary care for brief A&G, preferably to obtain a rapid answer to the problem. There may be difficult social or psychological patient issues which impact on management that need to be considered. In the past, with endocrine services overloaded, this might have been provided by a commercial platforms but are often not locally based and whilst commissioners should ensure providers are familiar with local clinical pathways and services, the lack of local familiarity can potentially lead to unnecessary delay. This brings also the disadvantage of introducing a fourth party who may not be aware of local protocols and care pathways, and therefore not able to suggest any option other than to refer. This brings with it the potential for unnecessary delay, poor patient experience and cost implications, as well as issues due to the interaction with the fourth party falling outside the usual primary/secondary care records.

Nevertheless, GPs may value the ability to get rapid advice and many endocrinology services offer telephone, email or online chat for straightforward advice.

**Referrals**
Electronic referrals (e-referrals) are now the norm and contain GP system extracts of the patient records. These provide useful background information in addition to the referral question, such as recent test results, past clinical conditions and medication. Referrals can be booked directly, where a patient receives a clinic date without any intervention (directly bookable service) or dealt with by secondary care clinician triage (referral assessment) with allocation to a specific clinic or another outcome.

If a referral assessment system (RAS) is used, a large proportion of referrals can be managed initially by recognition of the specific concern raised. This can often lead to referral directly to investigations and the test results can be reported to patient and GP with reassurance or explanation. Those explanations can be face-to-face, by telephone or by letter/email, either standard or personalised depending on the implications of the results.

With the additional information in the e-referral, a proportion of referrals can be better managed by detailed A&G to both patient and GP.

The response to a GP can be an opportunity to validate their approach and/or provide education with specific management algorithms, links to guidelines or personalised local advice in accessible formats. This can include encouraging appropriate pre-referral investigations for common conditions.

**Combining referral and A&G into one electronic portal**
A single e-referral portal, e.g. the NHS e-Referral Service (e-RS), can be used for all referrals whether for A&G or direct referral.

**Advantages**
- Allows rapid triage of patients with endocrine disease based on need, with immediate response to primary care.
- Copies of all letters are sent to patients / GPs and explain (if necessary) why a clinic appointment is not needed.
- Letters are addressed to patients as needed, with the offer to contact with concerns/queries.
- All letters also form part of EPR so that there is a clear audit trail of actions within the EPR.
- Immediate endocrine testing as needed prior to clinic appointment or ahead of giving advice.
- Secondary care are able to see patients in a more timely fashion, with potential for extra necessary work up to be performed pre-clinic.

**Requirements for adoption of this approach**
- Appropriate job planning for secondary care, for large centres this is approximately IPA activity.
- Timely responses provided to primary care – suggested 48 hours where possible.

**Figure 4: Overview of suggested referral from primary to secondary care**
10.4.5 GIRFT recommendations around the primary/secondary care interface

The GIRFT report has highlighted two key areas where a change in the model of care and the interface between primary and secondary care is needed:

Recommendation 1A
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.

- Benefits of this approach: streamlining of the patient journey
- Risks of this approach: increase in primary care workloads

Recommendation 4A
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 (see below) to ensure that patients can access urgent treatment without unnecessary delay.

- Benefits of this approach: improved patient journey and care
- Risks of this approach: none

The working group considered these key areas to provide the recommendations detailed below:

Pre-referral investigation (GIRFT recommendation 1A)
Approximately 80% of all endocrine referrals in secondary care involve a dozen or so common themes, seen reasonably often in primary care for which some pre-investigation may be performed. Although it is desirable to have appropriate investigations prior to referral, this may not be feasible with GP workload, lack of certainty over appropriate testing or lack of access to certain tests. A flexible model for accepting what investigations are available from primary care is outlined in Appendix D. Examples for all the common themes will be available in the Society Resource Hub (SfE Resource Hub – link to follow).

Potentially urgent referrals (GIRFT recommendation 4A)
Situations where an urgent referral from primary to secondary care is needed, and/or rapid access to endocrine specialised opinion by telephone/rapid electronic means is needed. The following are suggested pathways for discussion between primary and secondary care:

- Suspected phaeochromocytoma
  - **Trigger:** Episodic symptoms/collapse and variable (high) blood pressure
  - **GP action:** Exclude thyrotoxicosis, start 24-hour collection for metanephrines. If symptoms severe, send urine, then ask secondary care to see face-to-face and for plasma metanephrines

- Clinically suspected Cushing’s syndrome
  - **Trigger:** Clinical/biochemical suspicion
  - **GP action:** request face-to-face appointment in secondary care for assessment

- Severe thyrotoxicosis
  - **Trigger:** Typical symptoms, but severe
  - **GP action:** Check for eye symptoms/signs, TRAB and TPO autoantibodies. If T4 > 2x ULN, start carbimazole 40mg daily with beta blocker (unless contra-indicated) in primary care and urgent referral

- Severe hypercalcaemia
  - **Trigger:** corrected serum calcium >3.0 mmol/L with symptoms; corrected serum calcium >3.5 mmol/L even without symptoms
  - **GP action:** encourage high oral fluid intake where possible and urgent referral to be seen within 1-2 weeks.

- Severe Hypocalcaemia
  - **Trigger:** corrected serum calcium <1.8mmol/L without symptoms or <2.0mmol/L with symptoms
  - **GP action:** same day referral to endocrine unit or A&E

- Adrenal crisis
  - **Trigger:** any clinical or biochemical suspicion
  - **GP action:** where possible take serum cortisol sample, but if clinical suspicion high then administer i.v. and hydrocortisone 100mg i.v. and urgent referral for inpatient/ambulatory unit review by endocrinology/emergency department.

10.4.6 Communication from secondary care following virtual assessment

We provide the following suggested checklist for follow-up communication after a virtual assessment in secondary care. The Professional Record Standards Body also provides examples of good outpatient letters.

- Write directly to the patient, copied to the GP
- Make any additional comments/actions for the GP visible to the patient
- Explain why the assessment was virtual and what that means

Tell the patient and GP what is being recommended and why
• Give a clear personalised management plan for both patient and GP, particularly if the virtual clinic results in a discharge
• Give the patient an opportunity to contact using a telephone number and/or an email address
• Consider offering patient-initiated follow-up if an immediate discharge is likely to be distressing or contentious.

10.4.7. Discharge from secondary to primary care

There are a number of challenges to consider around discharge from secondary to primary care.
• Secondary care clinics may ‘case hold’; continuing to review patients when it is not necessary
• Consultant’s may have a lack of confidence in primary care’s ability or willingness to monitor
• GPs have varying levels of confidence about endocrine conditions
• Many patients may prefer follow-up in their GPs surgery, if available
• The ease of access to advice in secondary care is valued by both patients and GPs
• Workload in primary care is high, especially post-COVID-19
• Some secondary care services have well-established/longstanding monitoring/recall systems in place which work well, and already perform well for specific conditions.

GP practice systems are generally good for automatic recall and flagging of scheduled investigations or reviews outlined in shared care agreements or personalised management plans. However, primary care (including GPs, nurse practitioners, practice pharmacists) may need significant extra resources to carry out these plans, as well as a secondary care point of contact for case queries or discussion.

Discharge with management plan and re-referral criteria

We provide examples below of situations in which it may be appropriate to discharge from secondary care to primary care, having provided a management plan and criteria for re-referring to secondary care.

• A patient with previously autoimmune thyroid disease could have their annual thyroid function test in primary care with re-referral criteria
• A patient with mild/moderate hyperparathyroidism can have monitoring at intervals, with sequential checking of adjusted calcium and bone density
• A patient with testosterone deficiency can have shared care for I.M. testosterone supplementation, with annual safety bloods and checking of serum testosterone levels.

10.4.8 Patient-initiated follow-up (PIFU)

PIFU may be appropriate for some endocrine conditions. Patients are often open to PIFU as it may provide them with more control over their condition and reduce unnecessary visits to outpatient and primary care settings. Patients must be made aware that long-term PIFU (see below) may constitute quite a shift in the way that their care is being managed. For GPs it can reduce the frustrating ‘ping pong’ between primary and secondary care, and it unblocks secondary care capacity for referrals. However, it must be easy for patients and GPs to access advice or review from secondary care when required. It is essential that patients are not disadvantaged by be placed on PIFU rather than intermittent ‘routine’ follow up, and the patient’s level of understanding and engagement in their condition should help inform this choice (see 9.3.4).

Below we provide examples where interval or ongoing PIFU may be appropriate for endocrine conditions.

• Interval PIFU (time limited)
The patient is asymptomatic, but contacts if symptoms return. Likely best for manageable symptomatic conditions or relapse/exacerbations in a stable long-term condition.
Example: Thyrotoxicosis in remission for first year off anti-thyroid drugs. After that move to annual monitoring in primary care.

• Ongoing PIFU (open-ended)
This is suitable for patients with long-term conditions. They contact based on symptoms/concerns without requiring ongoing routine contact unless change in circumstances, new symptoms or periodic exacerbations that need clinical intervention from their endocrine team. The patient is remotely monitored (in primary care).
Whilst a challenge to traditional endocrine practice, consideration may even be given to this approach in some patients who might traditionally be thought of as requiring life-long annual specialised endocrine follow up. Ongoing access to endocrine nurse advice is needed. There may be opportunities with new technologies to monitor the patient at home for a range of conditions.
Examples might potentially include:
• A hypopituitary patient on stable replacement, with interval pituitary imaging scheduled as required
• A patient with classical Addison’s disease who has had no crises or medication change over the past one to two decades. U&E can be performed on annual basis in case of need for fludrocortisone adjustment.

• Other general situations where PIFU may be appropriate
• When patients are more than six months overdue for an appointment – note similar clinic frequency may not be needed in the future
• PIFU after non-attendance at clinic, to encourage engagement, rather than simply rebook
• Time-limited PIFU for clinical futility where there has been no improvement in clinical measures despite input from the clinic, or for clear non-engagement.
10.5 CLINICAL TRAINING

Specialist training in endocrinology has undergone significant challenges in recent years with difficult recruitment, pressures from General Internal Medicine (GIM), the development of a new curriculum and the roll out of IMT3 training and the four-year specialist training programme.

COVID-19 has created more challenges. While there is some regional variation, the majority of trainees experienced disruptions to training due to a combination of factors including: repeated redeployments, service changes, the postponement of examinations, personal illness or shielding. Many trainees have experienced significant psychological trauma during the pandemic, are tired and have not been able to take all their leave.

Whilst trainees have acquired different skills including leadership and teamwork during COVID-19, their exposure to endocrine disease, to allow pattern recognition and complex explanations to patients, has been significantly reduced. There remains uncertainty as to how much additional support the COVID-19 effort will need. There may be delays to completion of training for some if personalised training recovery plans cannot be achieved.

Future models of care will involve a combination of face-to-face, video and telephone consultations, dependent on both clinical need and patient choice. Models must be mindful of equality, challenges for ethnic minorities within the workforce, size of hospital and populations served. We have become accustomed to new ways of working with remote clinics and MDTs but need to build quality training opportunities into these digital interactions, even when service delivery pressures predominate. More regional and national training opportunities are needed, to ensure equality of training and experience, as is dedicated time in specialty.

The NHSE recovery plan (2021/22 priorities and operation planning guidance) states the need to ensure that the correct clinical placements are in place to allow trainees to progress as normally as possible. Trainers need additional time to ensure that this occurs.

The principles described below can be applied beyond postgraduate specialist endocrine training but this is the initial focus. Particular thought is needed on delivery of training for the new IMT3 training programme and condensing training into the four-year specialist registrar training commencing in August 2022. The Society for Endocrinology would strongly support the Specialist Advisory Committee in delivering a 1-2 year period of dedicated specialist training, without continuing GIM care or on-call, to achieve the training requirements, in line with other Group 1 specialties such as neurology, cardiology, gastroenterology and renal medicine.

10.5.1 Feedback from endocrine and diabetes trainees

A recent survey of training programme directors recognises the potential disruption and delay to training due to the lack of exposure to specialty during the COVID-19 pandemic. Individual trainee recovery plans are being advised by the Joint Royal Colleges of Physicians Training Board (JRCPTB).

The Young Diabetologists and Endocrinologists Forum (YDEF) conducted an online survey, which highlights the need for protected time for speciality training to achieve clinical competencies as defined by the mandatory curriculum. It also makes the challenges of the pandemic very clear, as the below extract from the survey shows.

**Impact of GIM burden on endocrinology and diabetes (E&D) training**

- 80% felt that service provision within GIM had resulted in reduced speciality exposure.
- 45% felt they had insufficient time to complete their Specialist Certificate Examination (SCE) during training.
- 92% believed that training time free of any GIM commitments would improve the specialist care they would provide to patients upon completion of training.
- The discrepancies between E&D and other specialties (particularly procedure-based specialties), with regards to protected training time, was highlighted.
- 95% acknowledged the vital role tertiary centre placements have on acquiring competencies, including exposure to rare diseases and attendance at MDTs.
- 92% agreed protected educational time to attend tertiary centres would help them achieve the required curriculum competencies, and so improve clinical care.

**The effects of the first COVID-19 pandemic wave on E&D training (Sept 2020)**

- The majority of E&D SpRs did little or no speciality work during the first wave of the pandemic, leading to trainees becoming ‘de-skilled’ and having ‘decreased confidence’ when managing patients with specialty-specific conditions.
- 89% felt that COVID-19 emergency rotas reduced E&D training opportunities despite almost all (98%) individuals partaking in online teaching.
- 91% expressed anxiety about the additional detrimental effect further waves would have on their training.

In some regions, the new IMT3 posts in tertiary centres may further compromise the endocrinology and diabetes trainee experience. Action is needed now to avoid further (potentially irreparable) damage to trainee morale and consequently recruitment.

Recovering training after COVID-19 will need:

- restoration and recovery of training opportunities
- time for study leave to catch up with regional and national training opportunities
- time for trainers to adequately provide training in clinics (and pre- and post-clinic)
- combination of small, local registrar-based sessions (to enhance trainee discussion) as well as national experts and forums
- minimum standards of training that can incorporate further COVID-19 surges or other pandemics without abandoning training completely, it should include essential MDTs and include continuing some clinics, educational meetings etc
- adapted training opportunities incorporating new ways of remote consultations.
10.5.2 Vision of dedicated endocrine training

For high-quality training in endocrinology, the pre-rotation checklist should include:

- basic consultation skills, including skills for video consultation and basic endocrine scenarios
- familiarity with consultations for common conditions including use of training in the virtual environment using best practice videos and simulations
- weekly presentation of cases by trainees.

The expected number of clinics for competence should be achieved in each rotation, including sub-specialty clinics. This will be discussed further through the Specialist Advisory Committee Competency Framework with new targets for 2022.

There should be networked links to MDTs and training in other centres to allow ‘catch up’ and focused training in certain areas.

An example of a dedicated endocrine specialist training timetable (without GIM) might be:

<table>
<thead>
<tr>
<th>AM</th>
<th>Monday</th>
<th>Tuesday</th>
<th>Wednesday</th>
<th>Thursday</th>
<th>Friday</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Clinic (endo sub-specialty)</td>
<td>Clinic admin</td>
<td>Training clinic (F2F and telephone)</td>
<td>Endocrine testing</td>
<td>Specialist consultant-led Ward Round (ward IPs or referrals)</td>
</tr>
<tr>
<td></td>
<td>Or urgent new clinic</td>
<td></td>
<td></td>
<td>Regional / national MDT</td>
<td></td>
</tr>
<tr>
<td>Lunch</td>
<td>Journal club (full team - monthly)</td>
<td>Regional MDT</td>
<td>Education meeting / governance</td>
<td>Grand Round</td>
<td>Clinical cases meeting (full team - weekly)</td>
</tr>
<tr>
<td>PM</td>
<td>Preparation for regional MDT QIP or Leadership projects /</td>
<td>Ward referrals GP advice and guidance (with consultant) Pre-clinic discussion meeting</td>
<td>X ray / Biochemistry meeting Inpatient Referrals</td>
<td>Clinic (thyroid)</td>
<td>Super specialist clinic (super-numerary) vs Outside specialty experience e.g. attending operation, one stop thyroid, oncology clinic</td>
</tr>
</tbody>
</table>

Evening * * * * *

* Training events could include: locally (site or rotation specific) arranged events and teaching/Society and other webinars including ABCD/YDEF arranged events. This may also include specialty on-call rota.

‘Trainees have acquired different skills including leadership and teamwork during COVID-19.’
10.5.3 Examples of tools to enhance training opportunities

The development of video consultations as a primary outpatient tool, with online MDTs and education meetings, means that clinical examinations are less frequent in the outpatient setting. However, opportunities to enhance competencies in clinical examination still exist in assessment units and inpatient referrals.

Generic skills
• Training modelled to fit the clinical priorities in the NHSE recovery plan include:
  • continuing to prioritise patients on waiting lists; reviewing virtually when possible and encouraging PIFU where possible
  • enhancing communication with patients with ease of access to specialist nursing, A&G (via GPs)
  • following/developing pathways for common conditions to avoid clinic consultations
  • for remote (video or telephone) outpatient consultations to continue to at least match, and in many areas exceed, the 30% of total consultations as stipulated in the NHS Long Term Plan.

A summary of how to set up and perform remote consultations has been provided by a NICE appraisal.

Further training documents for conducting a video consultation are available and include:
Assessing patients for suitability of remote consultations: Remote consultations - GMC (gmc-uk.org)
Considerations when setting up remote consultations and how to perform: Practical advice on consulting with patients remotely - YouTube (MDU training video)
A short video about improving communication on video calls in primary care: Top 10 tips for successful GP video consultations - RCGP
Trainee assessment tools for video consultations: Workplace based assessments - RCGP

Clinics
Training needs to be adapted to ensure appropriate exposure to the entire curriculum whether at face-to-face or virtual clinics, with alternative supervision methods and delivery to achieve the appropriate competencies. The balance between having pre-clinic and post-clinic meetings will vary depending on stage of training, experience and case mix. Clinical and educational supervisors will need to discuss individual training needs with trainees to determine the optimum blend required. Supervisory time must be built into consultants’ job plans.

Optimised outpatient clinic training
Pre-clinic:
All patients discussed in a pre-clinic Teams/Zoom/distanced face-to-face meeting. SpR leads, having gone through entire list, and having accessed: all previous endocrine letters, relevant letters from other specialties, laboratory and imaging investigations. SpR provides a nominal plan for the clinic interaction and potential plan thereafter. The supervising consultant uses this to:
  • highlight specific issues to be considered in clinic — specific areas, likely tests and imaging needed, timeframes
  • illustrate and discuss an overall approach to patient and patients in general with specific questions
  • assess SpR knowledge and identify areas to improve.

Benefits:
• allows training issues to be handled at the first interaction of patient with SpR
• gives SpR more knowledge and confidence to perform role
• post-clinic, if further issues arise, these can be discussed with consultant as needed
• SpR is able to state to patient and GP that they have already discussed the case with the consultant
• tailors investigation(s) and saves time and money, enables appropriate discharge/follow-up of patients.

Clinic:
For multiple registrar clinics in parallel: it is possible to have a separate virtual platform running alongside the platform being used for the clinic itself – e.g. background Zoom meeting with consultant available throughout the clinic (equivalent of walk down the corridor) so that trainees can ask questions/discuss cases.

Dedicated training clinics (consultant supervising registrar) in person or virtually while service recovery continues.

Post-clinic:
Post-clinic meetings allow discussion of patients and modification of care pathways as needed.

Benefits:
• allows trainee and trainer assessment of trainee knowledge and approach
• issues and care pathway/investigations from clinic can be discussed with consultant as needed
• tailors investigation(s) and saves time and money, enables appropriate discharge/follow-up of patients.

In addition, a virtual e-whiteboard for ongoing patients of interest (EPR) is a useful tool for trainees to follow and share their experience of patients.

The multidisciplinary meeting in endocrinology as a Capability in Practice (CIP).
The management of endocrine disease often involves multiple specialities, including surgeons, neurosurgeons, oncologists, radiotherapists, ophthalmologists, radiologists and endocrinologists. Discussing individual patients with others in MDTs is an essential part of direct clinical care and training to be a consultant. Being able to chair such meetings is an important skill.

During training, exposure to several possible MDTs is an important CIP for a consultant endocrinologist. Pituitary, neuroendocrine tumour, adrenal, parathyroid and thyroid MDTs are all essential to good clinical care.

Since the COVID-19 pandemic, many such meetings have very successfully moved to online platforms and over the last year clinicians have learned to use these tools
effectively. This has helped to extend multidisciplinary liaison across multiple trusts. We now have regional MDTs, where clinicians from multiple sites can log in and present their patients to assembled experts, and get an opinion about patient care and an MDT outcome.

Trainees must be involved in such meetings throughout their training, as observers and, more importantly, as active participants. Trainees must present patients they have seen to the regional MDT, take on board the expert advice, and act on the outcomes. In the future, having ‘visiting rights’ to MDTs external to the rotation, or national MDTs, will further enhance experience.

Evidence of involvement in such MDTs should be logged on the e-portfolio and the interaction that the trainee learned should be countersigned in the same way that case-based discussions are documented.

An example of a remote pituitary MDT can be found on YouTube (with permission from patients involved).

**A&G as a model training tool**

This process represents a fabulous training opportunity supervised by the consultant and goes beyond clinical management as it also educates on service configuration. The referrals can be used post-event purely as a training tool with the supervisor asking the trainee how they would do things, or in real time under supervision.

**Nurse and patient-led training opportunities**

Several endocrine centres have a well-established Specialist Endocrine Nursing Team and nurse-led services including clinics, endocrine investigation and treatment, in-patient services and community services. These represent key opportunities for training including those for practical skills in dynamic function testing, endocrine treatment, patient counselling and patient education, and are useful not just for endocrine nurses but also for SpRs and medical students. Some examples of nurse-led clinics are detailed in Appendix E. In addition, PSGs are keen to involve expert patients to embed the patient journey into training, and example video consultations are being developed.

**Self-directed, regional, national and international training opportunities**

Attendance at regional, national and international meetings is essential for continued professional development in areas that may have less of a focus within local training programmes, or as an opportunity to access current and cutting-edge presentations in areas of particular interest. To meet these demands during the pandemic, learned societies and other bodies have rapidly developed online events and programmes, supported by on-demand resources post-event.

- Online conferences, including: SfE BES meeting, the Society Clinical Cases meeting, European Congress of Endocrinology, ENDO, Diabetes UK, Northern European Young Diabetologists Meeting, UKINETs, ENETs, the International Pituitary Congress and other subspecialty conferences
- Specific webinar series to provide continued education and the opportunity for community engagement, including: the Society’s Clinical, Research and Endocrine Nurse Skills webinar series; the International Society for Endocrinology webinars; YDEF/ASO webinar series; The Royal Society of Medicine series on genetics in endocrinology and the ENETS free webinar series.

- Postgraduate training courses, including: the European Society of Endocrinology (ESE) postgraduate training course and the British Society for Paediatric Endocrinology and Diabetes (BSPED) summer school.
- Targeted training, including: Manchester weekend Diabetes and Endocrinology SCE course; many local and regional rotation teaching, especially using tools such as ‘Menti’ voting engagement; case-based discussion by trainees with expert consultant panel.

The move to online provision resulted in far greater reach, suggesting that online access may in fact result in trainees being able to access a greater variety of opportunities than before.

It is essential that study leave time and study budgets are maintained to pay for registration to these events. This may match the standard in-person attendance costs, albeit without the travel and accommodation requirements.

For trainees requiring a more comprehensive coverage of the knowledge-based curriculum or who wish to pursue an award-bearing degree, there are options available using distance learning (including Barts MSc Endocrinology and Diabetes and various MSc courses in Diabetes e.g. Leicester, South Glamorgan). These require a very significant time commitment that may be a barrier to some.

Some trainee-led and trainee-developed learning opportunities that provide a different means of accessing learning and interaction with a learning community also exist:

- real time: SIMBA Birmingham
- on demand: Virtual Medical Educators and COMICs

A single, national portal itemising all endocrine training opportunities is required to allow easy access for all.

**10.5.4 Future vision**

Further projects, under development, can help ensure that we use our networks across the UK to create equivalent trainee opportunities.

**MDTs**

- National MDTs in areas of super specialist interest. This is already happening in thyroid cancer, while opportunities exist to do the same in neuroendocrine tumours, complex pituitary, adrenal and bone. This could be a regular national MDT or a rotating ‘open’ MDT in different centres to enhance training opportunities. This can also involve development of a national endocrinology email advice group as a larger MDT experience to gain advice.
- Encouraging re-planning of the training timetable to allow registrars to attend regional MDTs weekly throughout their training, whichever hospital they are located in. Other possibilities include additional slots to apply to ‘visit’ an MDT in another region to gain experience of how to manage a condition or see an MDT being run differently.
- Training videos of MDTs to demonstrate examples of MDT interactions. This can be expanded to different regions to show different MDT styles.
Following the patient journey

• A possibility is to have trainees continue the same virtual clinic over four years, regardless of the location of their training rotation. This would allow them to follow individual patients’ journeys and gain more complete experience in ongoing care.

• Training videos in which patients describe their patient journey and the impact of their interactions with healthcare professionals at key moments.

• Examples of standard clinic interactions with virtual or real clinic experiences, shared within the endocrine community e.g. Graves’ disease, hyperparathyroidism, prolactinoma.

• Attendance at virtual PSG meetings, to understand the peer support and the online navigation that patients go through. We envisage working with PSGs regionally and nationally to have ‘slot availability’ for registrars to become involved.

Simulated (SIM) learning experiences

• Shared SIM training with case scenarios. An example of SIM learning of a COVID-19 scenario is available from e-Learning for Healthcare. Many centres have done SIM training scenarios in endocrinology – this could be expanded for adrenal crisis, diabetes emergencies, hypoglycaemia, etc.

• Virtual reality is being developed in medical schools and surgical scenarios and can be useful to demonstrate a more ‘real life’ training scenario with augmented reality. Examples include:
  • GIGXR | HoloPatient - YouTube
  • Video HoloPatient/HoloHuman

The Society for Endocrinology's ongoing support

• The Resource Hub, which will hold educational resources and enable the sharing of good practice, will be held in the Members’ Area of the Society website (SfE Resource Hub – link to follow).

• Continuation of the provision of training opportunities through the peer review process. Society committees and leadership opportunities (in line with the new curriculum). These include: SpRs on Clinical Committee, Early Career Steering Group, Practical Skills Grant, peer review, Leadership and Development Awards.

• Assessment of meeting delivery and content and, if necessary, the alteration of them to fit the above principles - for example ‘Endocrine Update’.

• Development of virtual focus groups (trainees) to build the ‘ideal model’, in conjunction with other organisations (such as ABCD, YDEF).

• Email group network (analogous to the thyroid cancer email network).

• Wider Society support for training of the MDT, including new endocrine specialist nurses (as suggested in the GIRFT report).

• Clinical genetics plays an increasingly important role in all areas of medicine with specific examples being relevant to endocrine and endocrine oncology practice. Clinicians are now encouraged, following appropriate consent, to arrange diagnostic tests for a range of specific endocrine conditions according to the NHS England National Genomic Test Directory. Training in the implementation of testing and the interpretation of the results, especially for variants of unknown significance (VUS) is needed and this is being supported by the Society working in partnership with NHSE.

Training recovery comes at a critical time with pressures on service recovery and transformation to a four-year registrar training programme. This provides an opportunity to create world-leading endocrinology training, enhancing recruitment to the speciality and securing greater future strength for the discipline. To achieve this, time and resource are needed for both trainees and trainers.
Endocrine Nursing

The endocrine nursing section of the Society Resource Hub should be used to access relevant training materials, job plans, guidelines and protocols from other endocrine specialist centres. The Hub links to the Society for Endocrinology Competency Framework for Adult Endocrine Nursing and RCN accredited Neuroendocrine Cancer Nurse Competency Framework. Via the Hub (subject to approval) there will be access to examples of how to use the framework in practice, tools to record progress in competencies, and training requirements for nurses as they progress through their career.

The GIRFT report highlighted insufficient numbers of nurses supporting specialist endocrine services. The Endocrine Nurse Committee fully supports the GIRFT recommendation of a minimum of one ESN per specialist centre, but this will need to be more for larger and busier centres.

Training and mentorship of nurses new to endocrinology is considered essential, to aid development and progression via a structured career pathway (from staff nurse, to ESN, to advanced nurse practitioner (ANP) and nurse consultant). Nurses in established roles should have the same level of support, in particular if they are taking on new specialist roles within endocrinology.

Endocrine nurses working in isolation should have access to an experienced ESN, ANP or nurse consultant to support their development and training in the field of endocrinology. If this is not available locally, the lead endocrinologist should ensure the nurse has access via the Society for Endocrinology to a recognised mentor.

Emphasis should be placed on succession planning and retention of staff with yearly reviews and business planning as appropriate, to grow the endocrine nurse service provision. Consideration for rotational training of junior ESNs should be considered in large endocrine centres, to expose endocrine nurses to nurse-led Services, patient education, inpatient care and endocrine testing. The role of the ESN in inpatient endocrine care should be further explored and developed to support inpatient endocrine services.

There is an increasing number of HCAs and nursing associates establishing a role in endocrinology, i.e. endocrine testing. The ESN is essential in providing guidance, training and support to this staff group.
APPENDIX A. ESSENTIAL COMPONENTS OF AN ENDOCRINE DAY CASE UNIT

To be effective, it is recommended that a day case unit should have:

- treatment/examination rooms with reclining day case beds
- clinical equipment (monitoring equipment, oxygen, resuscitation equipment, anaphylaxis kit, PPE etc)
- handwashing facility
- clean room for preparation of medication/treatment
- storage facility for medications (including those requiring refrigeration), equipment (e.g. needles, syringes, sharps boxes) and linens
- ice dispenser (or access to)
- functional kitchen (or access to)
- toilet facilities for patients and staff (or access to)
- IT and communication facilities (telephone, computer, printer)
- direct access to the laboratory (or blood sample spinning facility).

APPENDIX B. EXAMPLES OF HYBRID WORKING

These examples demonstrate different and hybrid ways of working. Each illustrates the process of referral, triage, clinics, outcome and the use of a clinical nurse specialist to deliver services, a mix of face-to-face, telephone and virtual clinics, work shared between the hospital and community, and the interplay between different specialties. These examples are intended to facilitate thought and discussion and to encourage service review and evaluation of similar services in other centres. These examples can be adapted for other endocrine conditions, with changes focusing on improving patient-centered care.

Suspected PHPT Referral

Automated/ AI - Clin biochemistry triggered to Primary Care (or direct to endo) if new high calcium/ inappropriate PTH

Diagnostic uncertainty

Electronic advice and guidance OR Consultant Connect available for Primary Care Patient Pass for internal referral A&G

Referral to hub from local DGHs

Based on local criteria/ NICE ‘Hub & Spoke’ model Patient Pass system Enables 2 way dialogue with local hospitals and databasing of referrals Automatically populates parathyroid MDT list

Parathyroid MDT

PHPT likely

Primary Care PHPT guideline support Standardised e-Referral triggers:

1. Pre-clinic investigations
   - DXA, renal USS
   - PTH, vit D, calcium, U&E etc.
   - Urine calcium tests
   - FRAX
   - CV QRISK
   - Frailty score
   - Could be done in Primary Care or via endocrine admin at triage

2. Electronic patient questionnaire/ PROMs
   - Symptom scoring, PMH, Drugs, FH etc
   - As part of patient portal
   - And some initial patient info

Virtual triage with results

Virtual triage uses:

1. Electronic Patient Record
2. Patient-initiated questionnaire
3. Pre-clinic investigation results (as detailed previously)
   - This determines diagnosis, urgency, suitability prior to patient being seen
   - Training opportunity for HSTs
   - Reduces need for clinic appointments and follow-up

Triage options:

- Urgent medical clinic (specific defined criteria e.g. calcium >3mmol/L, young age etc)
- Routine nurse-led clinic (patients not fulfilling urgent criteria but who need seeing)
- Virtual remote monitoring (long-term follow-up)
- Discharge

1. PHPT likely but intervention not required
   - Electronic A&G offered to GP
   - Triage to virtual appointment if appropriate for patient
   - Triggers virtual monitoring process, as appropriate

2. PHPT likely and potentially suitable for intervention
   - Triage to virtual or face to face appointment, as appropriate
   - Arrange pre-clinic localisation scans prior to clinic

3. PHPT unlikely
   - Discharge with electronic A&G
APPENDIX B

Common features
- Guideline supported for HCPs
- Mixture of virtual and F2F appointments as needed
- Electronic Patient Record (EPR)
  - Paperless clinics with good 2-way integration with primary care
- Use of patient portal for 2-way communication re:
  - Patient-reported symptoms
  - Portfolio of patient information (links to patient support groups, patient videos)
  - Bespoke info delivered by recorded video/audio message
- Electronic delivery of documents
  - to GP (EPR) and patient (patient portal/accuRx etc)
- E-prescribing into community for seamless care
  - e.g. for vitamin D, cinacalcet etc
- Blood tests requested electronically
  - Prior to clinic and done in community hubs
- All patients databased
  - Admin-supported or EPR function for audit/research
- Training opportunities (nurses and doctors)

Specialty referral
- Urology/Genetic/Other
- Electronic referrals

Surgical referral
- Electronic referrals
- Joint clinics if needed

Further investigations
- Request via EPR
- Review results virtually

Discharge or Transfer care
- Back to primary care or referring hospital if appropriate with virtual support (email/Patient Pass) as needed
- Enable integration and dialogue between centres

Virtual monitoring
- Guideline supported
  - For patients who need monitoring as not currently suitable/desiring surgery
- Automated/admin-supported:
  - 6 monthly biochemistry (calcium, PTH, U&E)
  - 2-3 yearly DXA and FRAX
  - 2-3 yearly US renal for those with elevated urine calcium/previous renal calculi
- Patient initiated follow-up with annual symptom scoring
- AI algorithms/admin-monitored
  - To determine need for future clinic follow-up

Osteoporosis treatment
- Guideline supported
- Use of community IV zoledronic acid (Community IV service), when appropriate
- Community initiation and monitoring of Denosumab, when appropriate
- E-prescribing for Vitamin D, bisphosphonates etc
- Patient initiated follow-up if further fractures

Parathyroid MDT
- Virtual to allow attendance from interested parties local hospitals
- Outcomes via Patient Pass
- Training opportunity for HTRA/nurses

Medical treatment
- E-prescribing for Vitamin D, cinacalcet etc when appropriate
- Automated monitoring through virtual monitoring service may be suitable for some
- Patient-initiated follow-up if worsening symptoms/consequences

Clinics

Parathyroid medical

Parathyroid nurse

Virtual monitoring

CLINIC OUTCOMES
Example 2. Birmingham Queen Elizabeth Hospital Thyrotoxicosis Service (QuETS)

Referral
- ERHA
- Advice and Guidance
- Triage
- Pre-clinic blood test

Initial Consultation
- Face-to-face
- Virtual/telephone/remote
- Referral to QuETS
- Referral for radioliodine
- Discussion with surgeon about thyroidectomy if required
- Referral to joint TED clinic if needed

Treatment Monitoring
- QuETS protocol
- QuETS welcome letter
- QuETS info leaflet
- QuETS letter templates
- Radioliodine patient info leaflet

Review and Follow-up
- Consultant review
- Long-term follow-up
- Discharge protocol
Thyroid (QuETS) - ERHA
Advice Conversation

15-Apr-2021 10.18

Dear Colleague,

I shall be grateful for your advice on this 62 year old lady who has been under the care of the Dermatologists with lichen planus and also pruritis particularly affecting the buttocks and arms. They have questioned whether or not these symptoms could be related to her thyroid function.

She had a thyroid lobectomy in 1997 for carcinoma and has been on Thyroxine since. Her levels have always shown near-normal replacement with T4 between 15 and 22 and TSH between 0.02 and 0.05. I have always understood that this range is preferred in patients post-lobectomy.

Her most recent test in March done at the Hospital showed T4 14.4 and TSH 0.03 and we have been asked to find out if this could be contributing to her symptoms. Her current dose of Levothyroxine is 125mcg daily.

I look forward to hearing from you.

Dr K Vamma
Thyroid (QuETS) – Pre-clinic blood tests
Thyroid (QuETS) – Initial Consultation

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<tr>
<th>History</th>
<th>Thyroid disease before current episode</th>
<th>Smoking/alcohol history</th>
<th>Occupation</th>
<th>Obstetric history</th>
<th>Physical signs at presentation</th>
<th>TED</th>
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**Thyroid disease**

- Thyroid disease
- Family history
- Social history
- Previous history
- Current symptoms
- Past history
- Physical examination
- Laboratory tests
- Imaging studies
- Thyroid ultrasound
- Thyroid function tests
- Thyroid biopsy

**Thyroid disease before current episode**

- Duration of symptoms (months)
- Change in weight
- Tiredness
- Heat intolerance
- Cold intolerance
- Bowel frequency increased
- Bowel frequency decreased
- Mental disturbances
- Thyroid/thyroid swelling
- Neck pain
- Shortness of breath

**Impression/initial diagnosis**

- No change
- Yes
- No

---

**Presenting complaint:**

- Duration of symptoms (months): 3
- Change in weight: No
- Tiredness: Yes
- Heat intolerance: No
- Cold intolerance: No
- Bowel frequency increased: No
- Bowel frequency decreased: No
- Mental disturbances: No
- Thyroid/thyroid swelling: No
- Neck pain: No
- Shortness of breath: No

**Diagnosis:**

- No change
Thyroid (QuETS) – Referral for radioiodine treatment
Thyroid (QuETS) – Thyrotoxicosis Management Guideline

**Referral from GP**
1. Triage
2. Standard letter to GP to start CMZ and overview of the service

**1st appointment (Medical Clinic)**
1. Diagnostic work-up
2. Discussion about 3 treatment options.
3. Written warning regarding agranulocytosis whilst on ATD
4. Provide patient information leaflet on 131I
5. Referral to nurse-led monitoring
6. Provide QuETS patient info
7. Arrange follow-up (see below)

**Nurse-led monitoring**
1. Inclusion criteria:
   - ATD titration
   - Preparation before definitive treatment with 131I or surgery
   - Monitoring off ATD (12 months)
   - Annual check for patients on long-term ATD
   - 4-weekly TFT check following 131I for 4 months, increasing to 2-monthly thereafter until euthyroid off ATD for 12 months or established on levothyroxine (with normal TFT)
2. 6-weekly blood test until control of thyrotoxicosis
3. 3-monthly TFT monitoring when thyrotoxicosis is controlled
4. Remote monitoring of results supported by telephone consultation and letter
5. Face-to-face appointment at 12 mons or as required
6. Blood test arranged at GP surgery or in out-of-hours dedicated phlebotomy clinic

*First appointment for 131I will be face-to-face at 4 weeks following 131I administration. Subsequent monitoring will be remote.

**2nd appointment (2-18 mon) (optional)**
1. If first line 131I treatment or surgery by patient choice or if indicated (toxic nodular disease)
2. Patient concerns or unanswered questions.
3. Clinical concerns (e.g., patient not responding to treatment)
4. Confirmation of diagnosis of thyrotoxicosis

**Routine appointment at 18 mon**
1. Plan date for discontinuation of ATD if TSH in normal range
2. Check TRAB just before discontinuation of ATD at 18 mons

**TRAB <3 IU/L and TSH normal at 18 mons**
1. Stop ATD
2. Monitoring in nurse-led clinic for 12 mons
3. Refer back to Medical Clinic for discussion of options if relapse

**TRAB >3 IU/L at 18 mons**
1. Continue ATD for 12 mons and then re-check TRAB
2. Re-discuss need for definitive treatment
3. Refer back to nurse-led monitoring until further TRAB measurement
4. Repeat this procedure after further 12 months if no definitive treatment given
University Hospitals Birmingham
NHS Foundation Trust

Department of Endocrinology
Thyroid Clinic
Queen Elizabeth Hospital Thyrotoxicosis Service (QuETS)

Prof. Kristien Boelaert, Consultant Endocrinologist
Mirtam Asia and Shirley Castro, Clinical Nurse Specialists

Heritage Building
Queen Elizabeth Hospital
Edgbaston
Birmingham B15 2TH

Telephone: 0121 371 6950
Email: EndocrineNurses@uhb.nhs.uk

If you have had tests, in general you will be informed of the results. Please leave at least 1 month after you have had the test before contacting the department for the results.

If you are due a follow up appointment and do not receive one by the planned time, please contact the department.

Following your consultation in the Thyroid clinic, you are now being referred to QuETS (Queen Elizabeth Thyrotoxicosis Service) which is a remote follow-up clinic for patients with thyrotoxicosis.

I have enclosed a leaflet for your information. Please read carefully as this will explain in detail.

As part of your treatment and monitoring, it is important that you have a regular blood test. Your blood test will be done through one of our satellite phlebotomy clinics. It is very important that you attend your blood test appointment so we can ensure that you are on the right dose of thyroid medication.

Our phlebotomy clinic booking team will contact you at least 2 weeks before the requested date unless you need an urgent blood test.

If you have any concerns regarding your thyroid condition and thyroid medication while under our service, please contact us preferably by email (EndocrineNurses@uhb.nhs.uk) or by phone on 0121 371 6944/6947.

Prof. Kristien Boelaert
Consultant Endocrinologists
Thyroid Service

Shirley Castro
Clinical Nurse Specialist
Endocrinology
Welcome to the Queen Elizabeth Thyrotoxicosis Service, otherwise known as QuETS.

What is QuETS?
QuETS is a remote follow-up clinic for patients with thyrotoxicosis (an overactive thyroid gland). This clinic enables the treatment of your thyroid condition to be carefully monitored through regular blood testing while reducing the number of face-to-face clinic appointments. Face-to-face clinic appointments will still be part of your routine care.

Who is eligible for QuETS?
Patients who have been referred to the Thyroid Clinic at Queen Elizabeth Hospital Birmingham with a diagnosis of thyrotoxicosis and are receiving either a course of anti-thyroid drugs or have received radiiodine treatment.

How does QuETS work?
- A blood test will be arranged by the thyroid specialist nurse (see arranging blood tests). Blood tests are usually performed every six weeks until your thyroid function is under control. This is then moved to three or six-monthly.

Contacting us
If you are unable to attend an appointment or you would like to contact the service to discuss QuETS in more detail, please call 0121 371 6950 or email EndocrineSecretaries@uhb.nhs.uk

Arranging blood tests
We will arrange blood tests at the Queen Elizabeth Hospital in the Thyroid Phlebotomy Clinic (appointment letter will be sent). If your GP sends blood tests to the Queen Elizabeth Hospital, you may have an option to have a blood test at your GP surgery, if your GP is happy to do so.
Thyroid (QuETS) – Clinic letter templates
Thyroid (QuETS) – Radioiodine patient information leaflet

Queen Elizabeth Hospital Birmingham
Part of University Hospitals Birmingham NHS Foundation Trust

Thyrotoxicosis and its treatment with radioiodine

Delivering the best in care

UHB is a no smoking Trust

To see all of our current patient information leaflets please visit www.uhb.nhs.uk/patient-information-leaflets.htm
APPENDIX C. EXAMPLES OF ALTERED PRACTICE ON THE PRIMARY AND SECONDARY CARE INTERFACE

These centres were asked to describe how they dealt with the pressures during and after the COVID-19 pandemic, and what innovations that generated. Those particularly relevant to the interface between primary and secondary care have been summarised.

Cardiff
- Electronic referral assessment system (RAS) to book into appropriate clinic or transfer to another service, is also the route for most Advice and Guidance (A&G), used rather than the e-advice system
- They have found telephone consultations well received and good for majority of new and follow-up patients.

Exeter
- RAS with consultant review of new referrals, leading to more A&G letters, and ensuring all tests done prior to first appointment
- Infrastructure for remote video and telephone consultations set up
- All follow-up appointments remote unless a specific need for face-to-face identified
- Endocrine nurses prompting patients for blood tests prior to clinic
- Thyroid clinics separate with blood test forms mailed out prior to clinic.

Guy’s and St Thomas’ Hospital, London
- Easy access for GPs to rapid discussion and advice RAS with consultant vetting to appropriate clinic/member of staff.
- Standardised pathways for common endocrine conditions.

Leeds
- Detailed pre-clinic questionnaires and testing in hyperparathyroidism
- Nurse-led virtual clinic for low risk thyroid cancer, with discharge and PIFUs/Nurse-led microprolactinoma clinic with stopping protocols to check for remission.

Oxford
- Pre-testing for common conditions pre-clinic with standard protocols
- Similar pretesting protocols for annual review clinics in various conditions.

Plymouth
- Virtual patient group and videos for obesity clinic
- Online teaching sessions for primary care
- Shared care protocols for testosterone injections.

Sheffield
- All referrals/requests for A&G in one portal
- Detailed consultant triage of all referrals
- Detailed A&G letters as needed
- Pre-clinic testing as needed.

Southmead Hospital, Bristol
- Detailed description of a referral assessment system.
- Pathway for common endocrine conditions agreed with local CCG to inform potential referrers and reduce unnecessary referrals
- E-referral direct booking slots turned off
- Referrals received and triaged by consultant. Outcome sometimes differed from referrer’s request
- Possible outcomes: A&G, remote consultation (telephone or video), face-to-face consultation
- Pre-consultation investigations requested if not already performed and feasible in primary care
- Pre-consultation questionnaires and requests for self-examination also sent (BP, weight, ankle swelling).

University College Hospital, London
- Have an electronic patient portal as part of their electronic patient record allowing uploading of results and two-way communication between service and patient. Particularly useful for managing acutely unwell patients while shielding.

Whittington, London
- Virtual review of follow-up waiting lists during COVID-19.
- Involved review of most recent letters and results, writing to patients and GPs with management plan, request for blood tests and booking into appropriate clinic or discharge to primary care with management plan.
### APPENDIX D. EXAMPLES OF PRE-REFERRAL INVESTIGATIONS

Approximately 80% of all endocrine referrals in secondary care involve a dozen or so common themes, seen reasonably often in primary care for which some pre-investigation may be performed. Although it is desirable to have appropriate investigations prior to referral, this may not be feasible with GP workload, lack of certainty over appropriate testing or lack of access to certain tests. A flexible model for accepting what investigations are available from primary care is outlined with examples below.

### Sweating

<table>
<thead>
<tr>
<th>Presentation</th>
<th>Sweating/flushing</th>
</tr>
</thead>
<tbody>
<tr>
<td>Note</td>
<td>Sweating is a common concern and the cause is rarely endocrine. Options for management can be sought from dermatology.</td>
</tr>
<tr>
<td>First line investigations</td>
<td>Thyroid function, LH, FSH, and oestradiol/testosterone, as appropriate, and Hba1c</td>
</tr>
<tr>
<td>Second line investigations (could be facilitated by secondary care local agreement)</td>
<td>Urinary catecholamines/plasma metanephrines, IGF-1 (rare causes of sweating), urinary 5 HIAA if dry flush</td>
</tr>
<tr>
<td>Actions</td>
<td>Address any abnormality identified as appropriate</td>
</tr>
<tr>
<td>Referral to endocrinology if</td>
<td>Any endocrine test abnormal unless abnormality can be addressed in primary care</td>
</tr>
<tr>
<td>Key information to include</td>
<td>Blood work up and any second line investigations</td>
</tr>
<tr>
<td>Consider referral to other services if</td>
<td>Endocrine work up normal, refer to dermatology if no concerns about malignancy</td>
</tr>
<tr>
<td>Red flags to prompt urgent referral</td>
<td>Concerns about malignancy e.g. weight loss (not to endocrinology)</td>
</tr>
</tbody>
</table>

### Hyperprolactinaemia

<table>
<thead>
<tr>
<th>Presentation</th>
<th>Hyperprolactinaemia</th>
</tr>
</thead>
<tbody>
<tr>
<td>Note for patients on medication known to cause hyperprolactinaemia</td>
<td>If on antipsychotic or antidepressant or antiemetic medication known to cause hyperprolactinaemia (usually &lt;2500 mU/L). Ideally, a baseline prolactin should have been taken before commencing the antipsychotic/antidepressant to exclude an abnormality. If a baseline prolactin was not measured, you should consider pausing the medication for three days and rechecking the prolactin. If the level is normal, then, you can be reassured that the hyperprolactinaemia is medication-induced. Also refer patients, in whom you are unable to change their antipsychotic medication to a medication with less of an effect on prolactin, with symptoms of hypogonadism (reduced libido, erectile dysfunction, low testosterone, oligo/amenorrhoea or galactorrhoea).</td>
</tr>
<tr>
<td>First line investigations</td>
<td>Repeat prolactin (ensure macroprolactin has been measured if raised), thyroid function, LH, FSH, and oestradiol/testosterone, and renal function</td>
</tr>
<tr>
<td>Second line investigations (could be facilitated by secondary care local agreement)</td>
<td>If remains abnormal – TPO Abs &amp; TSH R Abs</td>
</tr>
<tr>
<td>Actions</td>
<td>Address any abnormality identified as appropriate</td>
</tr>
<tr>
<td>Referral to endocrinology if</td>
<td>Prolactin remains elevated and not related to macroprolactin or medication (see above)</td>
</tr>
<tr>
<td>Key information to include</td>
<td>Prolactin levels and blood work up and any second line investigations</td>
</tr>
<tr>
<td>Consider referral to other services if</td>
<td>Ongoing primary care concern about presentation despite normal prolactin – headache, subfertility (fertility services), management of PCOS (endocrinology)</td>
</tr>
<tr>
<td>Red flags to prompt urgent referral</td>
<td>Blood results demonstrating hypopituitarism, headaches, visual field defect</td>
</tr>
</tbody>
</table>

### Thyroid

<table>
<thead>
<tr>
<th>Presentation</th>
<th>Subclinical hyperthyroid (below normal TSH, normal T4 and T3)</th>
</tr>
</thead>
<tbody>
<tr>
<td>First line investigations</td>
<td>Repeat TSH, free T4 &amp; T3 in 3 months</td>
</tr>
<tr>
<td>Second line investigations (could be facilitated by secondary care local agreement)</td>
<td>If remains abnormal – TPO Abs &amp; TSH R Abs</td>
</tr>
<tr>
<td>Actions</td>
<td>If asymptomatic and no aetiology identified and no cardiovascular risk factors and under the age of 65 – specialist review may not be required particularly if TSH 0.1 mU/L or higher – arrange TFT checks every 6 months</td>
</tr>
<tr>
<td>Otherwise seek advice &amp; guidance/refer</td>
<td></td>
</tr>
<tr>
<td>Referral to endocrinology if</td>
<td>Symptomatic, aetiology identified, cardiovascular risk factors, 65 years or older</td>
</tr>
<tr>
<td>Key information to include</td>
<td>Blood work up, second line investigations</td>
</tr>
<tr>
<td>Consider referral to other services if</td>
<td>Ongoing primary care concern about presentation</td>
</tr>
<tr>
<td>Red flags to prompt urgent referral</td>
<td>Evidence of thyroid eye disease</td>
</tr>
</tbody>
</table>
# APPENDIX E. EXAMPLES OF NURSE-LED CLINICS

<table>
<thead>
<tr>
<th>Type of nurse-led clinic</th>
<th>Learning opportunities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adrenal tumour</td>
<td>• Assessing and screening of patients with adrenal incidentaloma.</td>
</tr>
</tbody>
</table>
| Adrenal insufficiency    | • Assessing and long-term monitoring of patients with glucocorticoid-induced adrenal insufficiency.  
|                          | • 1:1 and group patient education |
| Andrology                | • Initiating and monitoring gonadotropin therapy for induction of spermatogenesis.  
|                          | • Initiating and long-term monitoring of patients on testosterone replacement therapy. |
| Growth hormone           | • Initiating and monitoring growth hormone treatment. |
| Late effects             | • Remote and virtual monitoring of childhood survivors of cancer. |
| Osteoporosis             | • Initiating and monitoring osteoporosis treatment (zoledronic acid, denosumab, teriparatide).  
|                          | • 1:1 and group patient education |
| Pituitary                | • 1:1 and group patient education Assessing and screening of patients with pituitary adenoma.  
|                          | • Initiating and monitoring somatostatin analogue (SSA) treatment.  
|                          | • Initiating and monitoring pegvisomant treatment.  
|                          | • Initiating and long-term monitoring of patients on dopamine agonist treatment.  
|                          | • Telephone clinics and advice line. |
| Thyroid                  | • Long-term monitoring of patients with thyroid disorders.  
|                          | • 1:1 and group patient education |

**Endocrine investigations and treatment**

- Dynamic function testing (e.g. short synacthen test, insulin tolerance test, glucagon stimulation test, oral glucose tolerance test, corticotrophin releasing hormone test, water deprivation test, cortisol/ACTH day curve, TRH test, mixed-meal test, prolonged supervised fast test).  
- Practical experience in performing dynamic function test.

- Endocrine treatment (e.g. somatostatin analogue [SSA], Zoledronic Acid, Denosumab, testosterone)  
- Practical experience in preparing, administering and monitoring endocrine treatment.

- Patient education and support  
- Educating and supporting patients
‘The Society for Endocrinology is a good, welcoming and positive society that gives a lot back to its members and to those involved on its committees and Council. The outcomes of this review need to maintain and buoy that positivity.’