Patient initiated follow-up (PIFU) guideline in endocrinology services Worcestershire Acute Hospitals NHS Trust

This guidance does not override the individual responsibility of health professionals to make appropriate decision according to the circumstances of the individual patient in consultation with the patient and /or carer. Health care professionals must be prepared to justify any deviation from this guidance.

Introduction

Patient Initiated Follow Up (PIFU) service in endocrinology has specifically been designed for patients who are currently under secondary care for certain endocrine conditions, to allow them to access clinical teams if they feel they need to, rather than having a prearranged or regularly scheduled appointment.

The service helps to reduce unnecessary visits to hospital, reduce patient waiting times, reduce travel and parking costs and provide more flexibility for patients to choose when they require an appointment.

This guideline is for use by the following staff groups : Consultants, Registrars and Specialist Nurses in endocrinology.

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Key amendments to this guideline

Date	Amendment	Approved by:

Introduction

In England, the total volume of outpatient hospital appointments increased by two-thirds between 2008/09 and 2019/20, to 125 million a year with follow-ups accounting for two-thirds of all appointments. This is the largest increase in activity of any hospital service, and long waiting times, delayed appointments and rushed consultations have become increasingly common. The Covid-19 pandemic has only exacerbated these challenges, with the number of patients waiting for a first appointment with a specialist now more than six million – an increase of more than a third since the start of the pandemic. This has placed extra strain on services, which have struggled to keep pace with demand for some years. Part of the problem is that under standard pathways, patients with long-term conditions or following surgery are automatically called back for outpatient appointments at regular intervals (for example, every six months). These timings are not necessarily decided by clinical need or when a patient wants extra support. This means that when follow-ups do occur, they can fail to lead to further investigation or any meaningful change in patient management. Conversely, when a patient's symptoms or circumstances do change, they may experience a long wait for an appointment as capacity has been devoted to routine follow-up.

PIFU aims to give more flexibility and choice to patients over the timing of their care and allow them to book appointments as and when they need them rather than follow a standardised schedule. The rationale behind this shift is straightforward: one of the most fundamental challenges in outpatient care is the mismatch between patient need and access. Patient initiated follow-up (PIFU) describes when a patient (or their carer) can initiate their follow up appointments as and when required, eg when there are concerns about symptoms or circumstances change. A patient is put onto a PIFU pathway following discussion with and consent from the patient in line with the Ensuring high quality of care when using PIFU guidance. The patient remains under the care of the secondary care service.

Why use PIFU in endocrinology?

The common non-diabetic endocrine conditions (eg thyroid disorders, hyperparathyroidism, polycystic ovarian syndrome, male hypogonadism, obesity) affect at least 25% of the adult population. Endocrinology is predominately an outpatient speciality as many endocrine conditions are long-term conditions and therefore can be managed on an outpatient basis (Society for Endocrinology, 2022). Outpatient appointments have increased by 31% in the last five years (GIRFT 2021). The transformation of endocrinology outpatient services would therefore benefit a high proportion of endocrinology patients and staff.

PIFU provides an alternative to routine secondary / tertiary care follow up for people with endocrine conditions but who are not suitable for discharge to primary care. It gives patients more control over their condition and provides them with the opportunity to seek advice and clinical contact when it is clinically required. This may decrease requests by these patients for advice and guidance from GP practices and enables endocrinology services to keep slots free for patients who really need them. Many endocrine conditions often require long-term medication, monitoring and follow up by secondary care services. This indicates that PIFU may be suitable for a high proportion of patients with these conditions.

PIFU timescales, and action at the end of the timescale

When a patient is moved to a PIFU pathway, this will be valid for a predefined timescale. This timescale could relate to:

• the length of time after which the patient will need a review (eg notes review, face-to-face, remote consultation)

• the length of time after which the patient will be discharged.

It is important that the timescales attached to PIFU are clinically relevant, and ideally these would be personalised to each patient. The Patient initiated follow-up: template standard operating procedure recommends updating the clinic electronic system (eg PAS system) with the agreed timescales and actions for each patient.

- **Short term PIFU (time limited) (Discharge Pathway).**

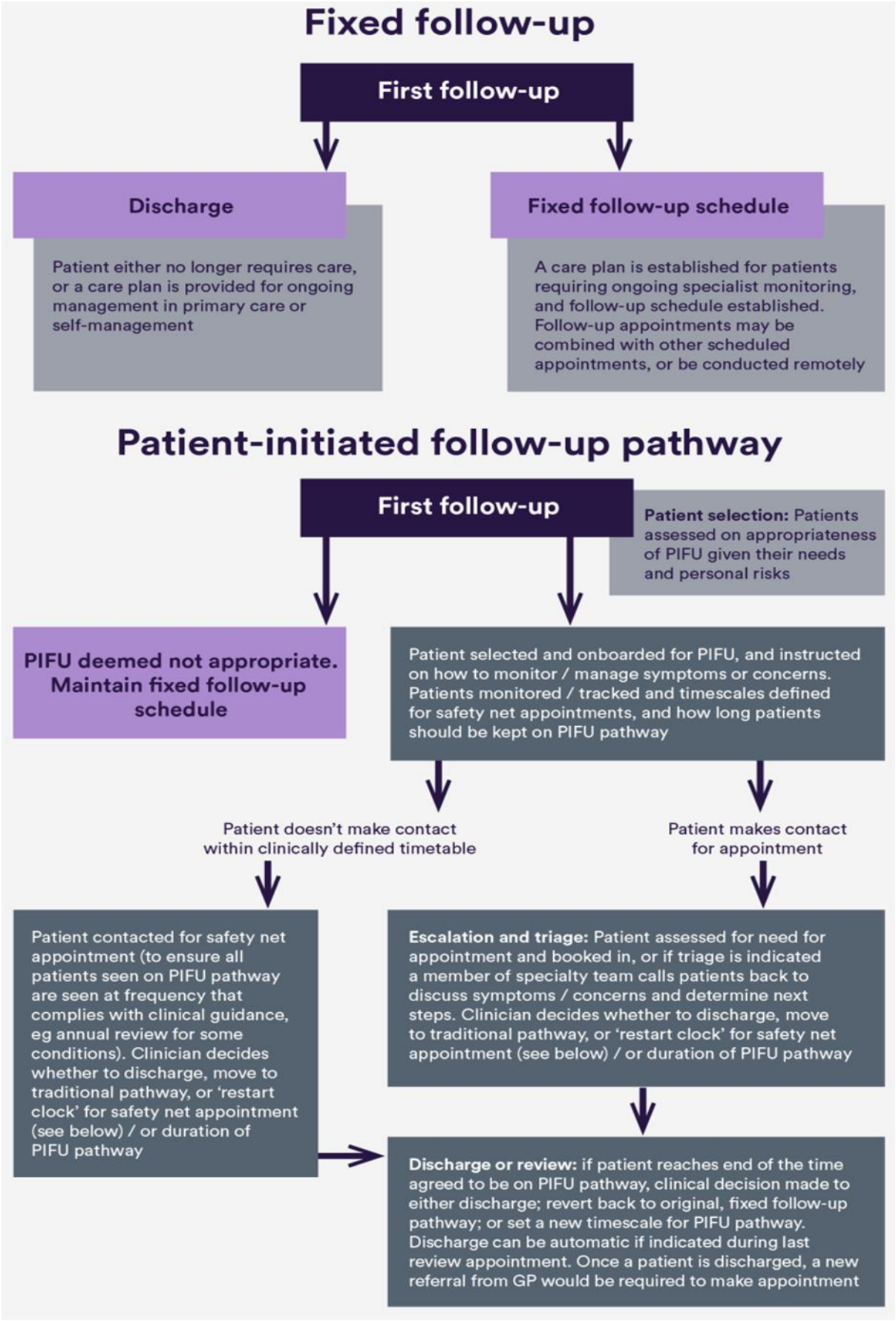
Open access for tests/advice during a fixed time. The patient is asymptomatic, but contacts if symptoms return. This is best for self-manageable symptomatic conditions or relapse/exacerbations in a stable long-term condition. Before commencing this PIFU pathway, the action at the end of the fixed period is agreed (discharge, notes review, face-to-face appointment).

Discharge to PIFU: once a 'discharge to PIFU' outcome is used, patient is discharged (upfront), if the patient contacts the team for an appt within the agreed timeframe, patients will be added back onto the waiting list.

- **Long-term PIFU (open-ended, ongoing PIFU) (Transfer Pathway).**

Ongoing access for patients to advice and regular investigations and tests. Patients make contact based on symptoms/concerns without requiring ongoing routine contact unless there is a change in circumstances, new symptoms or periodic exacerbations that need clinical intervention from their endocrine team. This approach will be suited to patients who might traditionally be thought of as requiring lifelong annual specialised endocrine follow up. These patients will often require routine tests and investigations and appointments for these will be scheduled alongside the PIFU pathway. Throughout this PIFU pathway the patient remains under the care of the secondary care service.

Transfer to PIFU: once a 'transfer to PIFU' outcome is selected, patient should be added to the outpatient follow up waiting list with appropriate target date for appt/review OR an appointment booked (if having regular appointments).


Fixed follow-up
First follow-up
Discharge
Patient either no longer requires care, or a care plan is provided for ongoing management in primary care or self-management
Fixed follow-up schedule
A care plan is established for patients requiring ongoing specialist monitoring, and follow-up schedule established. Follow-up appointments may be combined with other scheduled appointments, or be conducted remotely
Patient-initiated follow-up pathway
First follow-up
Patient selection: Patients assessed on appropriateness of PIFU given their needs and personal risks
PIFU deemed not appropriate. Maintain fixed follow-up schedule
Patient selected and onboarded for PIFU, and instructed on how to monitor / manage symptoms or concerns. Patients monitored / tracked and timescales defined for safety net appointments, and how long patients should be kept on PIFU pathway
Patient doesn't make contact within clinically defined timetable
Patient makes contact for appointment
Patient contacted for safety net appointment (to ensure all patients seen on PIFU pathway are seen at frequency that complies with clinical guidance, eg annual review for some conditions). Clinician decides whether to discharge, move to traditional pathway, or 'restart clock' for safety net appointment (see below) / or duration of PIFU pathway
Escalation and triage: Patient assessed for need for appointment and booked in, or if triage is indicated a member of specialty team calls patients back to discuss symptoms / concerns and determine next steps. Clinician decides whether to discharge, move to traditional pathway, or 'restart clock' for safety net appointment (see below) / or duration of PIFU pathway
Discharge or review: if patient reaches end of the time agreed to be on PIFU pathway, clinical decision made to either discharge; revert back to original, fixed follow-up pathway; or set a new timescale for PIFU pathway. Discharge can be automatic if indicated during last review appointment. Once a patient is discharged, a new referral from GP would be required to make appointment

Speciality-Level Documentation for Operational Functions

- Clinical protocols or guidance – needs revising/updating and creating.
- Target service response times and tracking systems for patients to ensure no black holes.
- PIFU timescales – already agreed at Trust level.
- Patient communications.
- Letter template needs adjusting.
- Safety net creation:
    - PIFU pathways comply with national guidance on frequency of assessment. If patients do not contact specialty, ensure they are contacted or offered an appointment.
    - Review processes for end-dates whilst on PIFU pathway.
    - Timely process for review of investigations (bloods, imaging etc) for PIFU pathway.
    - High-risk patients who do not attend appointments must be contacted to rebook.

Failing to initiate an appointment at the appropriate time and having poor outcomes as a result should be reported and investigated through established incident reporting mechanisms. Learning from the outcome of such incidents should be shared across PIFU services so any patient, for whom PIFU is not appropriate, is not put on this pathway.

- Analysis and refinement of booking processes, clinic slot availability and processes for PIFU triage.

Triage and advice

Applying a triage system to PIFU initiations will ensure that the patient's request is responded to in the most appropriate way. Within endocrinology this could include a phone call, written advice as well as face-to-face appointment. Telephone number for Endocrine admin staff and secretaries are included in patient information leaflet PIFU.

Target response times

Within endocrinology it is suggested that PIFU requests are triaged and actioned within three days. Where it is deemed an appointment, either virtual or face-to-face, is required, the exact timing will be driven by the clinical risk associated with the PIFU enquiry (urgent and non-urgent PIFU initiations) and waiting times for a consultation, however ideally it will take place within two weeks of the PIFU trigger. Clinician to instruct their secretary or admin staff to contact patient with triage outcome about waiting time for appointment.

Patients who request an appointment after their PIFU timescales have expired.

Booking team will confirm expiry date on the system and inform patients that they require a new referral through their GP.

Managerial Staff Responsibilities

Overall responsibility for the PIFU policy rests with the Divisional Director, Speciality Division (SRO, Outpatients High Impact Changes).
Division Medical Directors / Divisional Nursing Directors are responsible for ensuring all clinicians understand the process required for PIFU to be correctly implemented through the provision of adequate training.

Endocrine clinicians – consultant(s) or specialist registrar(s):

a. Agree a clinical protocol for PIFU (including clear inclusion/exclusion criteria) and set maximum waiting times for follow-up appointment.

b. Complete shared decision making (SDM) 30-minute module for training on how to discuss PIFU with patients. This can be accessed by "Your Learning Options" on (personalisedcareinstitute.co.uk).

c. Discuss PIFU with patients who meet the PIFU criteria and provide PIL. Educate patients on PIFU, consent, allow questions or for patient to raise any concerns and include in the clinic letter:

    i. Signs or symptoms to watch out for.

    ii. Triggers for requesting a review.

    iii. How to contact the service to book a PIFU appointment.

    iv. How long the patient will be on PIFU pathway for and the type of PIFU pathway they are on.

    v. Copy should be provided to the patient's GP.

d. Update the outcome form to decide if PIFU-D vs. PIFU-T. Additionally to decide if:

    i. Mode of follow-up: telephone, video, face-to-face.

    ii. Frequency of follow-up: 3, 6, 9, 12 and 24 months.

Endocrine clinical specialist nurse:

Nurse specialists can play a vital role in supporting the PIFU pathway for people with endocrine conditions. Their role could include arranging and monitoring routine tests and investigation results, as well as providing advice, guidance, nurse-led clinic appointments if appropriate as well as screening and triaging PIFU requests to appropriate clinics (nurse-led or consultant-led).

Administrative support

Getting it right first time (GIRFT, 2021) acknowledged the challenges in providing clerical and administrative resource support to clinics in the face of growing outpatient numbers. Increasingly, the use of PIFU may ease some pressures on clinics. However, it will be important to allocate some resource to patients on a PIFU pathway to ensure the monitoring of timescales, response times and timely action to requests from patients for an appointment. Within some endocrinology services currently offering PIFU, the medical secretaries are the point of contact for the patients triggering a PIFU request. The Patient initiated follow-up: template standard operating procedure describes the roles of the nominated PIFU administrator, co-ordinators and outpatient booking teams when offering a PIFU service.

Endocrine clinic reception staff:

e. To ensure correct coding of outcome forms to the electronic hospital system.

f. PIFU-Discharge pathway: Should select the relevant "PIFU Discharge – period combination" e.g. PIFU Discharge - 9 months.

g. PIFU-Transfer Pathway: Should select "Transfer to PIFU" and add the target date to the waiting list on the patient administration system (PAS).

Endocrine secretarial staff:

h. Once a patient initiates or requests an appointment on PIFU pathway, the secretarial team check:

i. Within the PIFU timescale. If they are out the PIFU window – redirect to see their GP.

ii. Establish the PIFU pathway in use:

1. PIFU-Discharge pathway: Open a new pathway and NOT reopen a closed pathway.
2. PIFU-Transfer pathway: Use pre-existing pathway.

iii. Decide the type of PIFU to offer using existing IOS:

1. Telephone consultation.
2. Remote video consultation.
3. Face-to-face consultation.

iv. Identify the appointment slot following clinical triage if required.

v. Book directly or asking the booking team to book the patient.

Personalised care

It is particularly important that there is a shared decision with the patient on whether PIFU is right for them and what the agreed PIFU plan is (eg the timelines and actions, including symptoms to look out for, PIFU timescales, when and how to contact the service, who within the service they will have contact with). The suitability of a patient for PIFU is both condition and patient dependent and requires an individualised approach and would benefit from using multidisciplinary patient care meetings to support the identification of potentially suitable patients.
Personalised care approaches operated through the PIFU pathway offer more effective ways to empower and enable patients to better manage their own condition.

Patients suitable for PIFU with PIFU plan

The following patient groups are suitable for PIFU with the secondary care endocrinology team likely to be the service responsible for the patients care. The type of PIFU would be a clinical decision in collaboration with the patient. For patients with an endocrine condition on a short term PIFU, 2-3 years would be a suitable timescale.

Pituitary disease

- patient in remission and stable (stable symptoms and biochemical parameter). Consider short term PIFU
- acromegaly cured for the last 10 years
- a patient with hypopituitary on stable replacement, with interval pituitary imaging scheduled as required

Adrenal

- Addison's disease: Stable, very well-informed, crisis-free for 10 years, on stable and optimum endocrine replacement therapy
- Cushing's in remission for >5 years and well and a recovered HPA axis
- Phaeochromocytoma after 5 years with no recurrence
- congenital adrenal hyperplasia on stable therapy and well-controlled for many years

Thyroid

- thyrotoxicosis in remission for first year off anti-thyroid drugs (if not suitable for discharge to primary care).
- cancer where there is stratified low risk of re-occurrence. Consider whether surgical or endocrinology team most suitable as responsible speciality.
- hypothyroidism with complications. Consider very short term PIFU (6-12 months). Discharge to primary care at the end of the PIFU timescale
- benign multinodular goitre with mild pressure symptoms / airway narrowing where there is uncertainty if it is growing. Consider whether surgical or endocrinology team most suitable as responsible speciality.

Calcium and bone

- osteoporosis on a treatment holiday
- osteoporosis on 3-5 year treatment with anti-resorptive agent

Parathyroid

- mild hyperparathyroidism currently managed conservatively.

Familial endocrine tumours (alongside timed appointments)

- **Hypogonadism**

- male patient on optimal maintenance dose of testosterone replacement therapy with no prostate pathology (if not suitable for discharge to primary care with or without shared care arrangements).

Routine tests and investigations

Most patients with endocrine conditions, require regular blood tests, investigations, and assessment to monitor their condition and treatment. These include.

• tests recommended in NICE guidelines on thyroid disease and hyperparathyroidism [primary]
• bone mineral density scans
• assessing fracture risk
• monitoring for renal stones pathways if appropriate
• blood tests; calcium
• monitoring for kidney stones requiring Urology referral
• monitoring for development of osteoporosis
• medication reviews at specified ages
• assessing cardiovascular risk

Patients on a PIFU pathway will need to have these tests and investigations completed, and secondary care will be required to monitor results as they return. Local agreements will need to clearly state.

• which service/who has responsibility for ordering and reviewing these tests
• where patients will have these tests conducted
• how secondary care will have access to the results
• the secondary care process for monitoring and actioning results as they become available.

The resulting agreement must be clearly communicated with the patient and be acceptable to them to support their engagement and for PIFU to be possible (for example can they access where the tests and investigations will be completed).

Which patients could benefit from PIFU in endocrinology services?

Examples of people who could benefit from PIFU in endocrinology are those:

• with stable chronic disease but who require regular reviews of clinical parameters by the secondary care service.

- who are well informed and have a desire to take more control over their condition.

• with self-manageable symptomatic conditions or relapse/exacerbations in a stable long-term condition
• patients who might traditionally be thought of as requiring lifelong annual specialised endocrine follow-up
• survivors of cancer who are in remission but have an on-going condition caused by previous cancer treatment and are unsuitable for discharge to primary care.

More detail about the types of endocrine conditions suitable for PIFU is detailed later in the suitability section.

Which people are less likely to benefit from being on a PIFU pathway in endocrinology services?

For people with endocrine conditions, the following examples are groups who may be less likely to benefit from PIFU, although it is possible that PIFU can be used alongside timed appointments for these patients:

•patient with any features which require physical assessment for example some types of goitre
• those who have received information about PIFU but choose not to receive care through this route
• the following clinical conditions (including but not limited to); active thyroid cancer and pituitary tumours, unstable Addison's disease (primary adrenal insufficiency), Graves disease, recent diagnosis of pheochromocytoma.
• where a patient is clinically suitable for discharge to primary care
• patients identified as at risk of experiencing health inequality as a result of implementing the PIFU pathway, for example.

- patients unlikely to be able to manage PIFU safely/successfully, such as unstable social situation, lack of confidence/ability to navigate a PIFU care pathway, etc
- concerns about safeguarding.

Patient-Specific Criteria for PIFU in Endocrinology

Inclusion

- Low risk of urgent follow-up care.
- Possessing health literacy and knowledge, skills and confidence to manage their follow-up care (patient activation).

- Confident and able to take responsibility for their care while on the PIFU pathway (do not have rapidly progressive dementia, severe memory loss or severe learning difficulty).
- Insight into changes in their symptoms and awareness of the indicators that might indicate need for service.
- Have tools to understand their condition (e.g. leaflets, devices or apps), their individual health status in reference to their condition and how to use these tools.
- Understand how to book follow-up appointments with the service and how long they will be responsible for this. For some patients, this task may be carried out by administrative staff in their care home or GP.

Exclusion

- Complex health issues.
- There is a clinical need to see patients on a fixed timescale (timed).
- Clinician has safeguarding concerns.
- Patient takes medicines that require robust and regular secondary care monitoring.
- Patient is unable to access the service easily due to poor accessibility to telephone or internet services.

Clinical Criteria for PIFU in Endocrinology Worcestershire Acute Hospitals NHS Trust.

Endocrine Condition	Short Term PIFU (Discharge Follow-up)	Long Term PIFU (Transfer Pathway)	Comments
Thyroid conditions	Access CNS PIFU Clinic in between consultant PIFU Clinic. **Graves' disease** Following confirmation of Graves' disease, discussed, and confirmed next line treatment and actioned for next line treatment referral. Remission and relapse of Grave's disease. **Other Hyperthyroid condition-** Following confirmation of Hyperthyroid disease, discussed, and confirmed next line treatment with patient and completed action for next line treatment referral.	Access CNS PIFU Clinic in between consultant PIFU Clinic. **Graves' disease** Following confirmation of Graves' disease, discussed, and refused or not suitable for next line treatment. **Other Hyperthyroid condition-** Following confirmation of Hyperthyroid disease, discussed, and confirmed next line treatment but refused or not suitable for next line treatment. **Hypothyroid.**	Required shared care pathway with ICS to reduce the list of patients and smoothen the flow out from department.

	Hypothyroid. Following confirmation of Hypothyroid disease, discussed, completed investigations, confirmed treatment and plan with patient.	Due to hypopituitarism and decided to follow-up regular base.	
Adrenal		**Addison's disease.** Adrenal insufficiency treated and stable conditions. CAH treated and stable condition. Non classical CAH treated and stable conditions. **Adrenal incidentaloma.** Cortisol secreting adenoma (Cushing's) treated and stable condition. Aldosterone secreting adenoma (Conn's) treated and stable condition. Phaeochromocytoma treated and stable condition. Carcinoma (any adrenal hormone) treated and stable.	Required shared care pathway with ICS to reduce the list of patients and smoothen the flow out from department.
Pituitary	Isolated Growth Hormone Deficiency. Treated and stable isolated Prolactinoma.	**Stable hypopituitarism** Low or no risk hormone deficiency or treated hormone deficiency and stable condition. (Assess the QoL and Complications when	Required shared care pathway with ICS to reduce the list of patients and smoothen the flow out from department

		deciding PIFU pathway) Acromegaly in remission and stable condition. Treated and stable Diabetes insipidus. Treated and stable SIADH. Treated and stable Prolactinoma. Treated and stable Cushing's (ACTH dependant).	
Parathyroid	Access CNS PIFU Clinic in between consultant PIFU Clinic **Primary Hyperparathyroidism** Following confirmation of Primary Hyperparathyroidism disease, discussed, and confirmed next line treatment with patient and completed action for next line treatment referral.	Access CNS PIFU Clinic in between consultant PIFU Clinic. **Primary Hyperparathyroidism** Following confirmation of Primary Hyper parathyroid disease, discussed, and confirmed next line treatment but refused or not suitable for next line treatment. **Hypoparathyroidisms** Treated and stable patients.	Required shared care pathway with ICS to reduce the list of patients and smoothen the flow out from department
Bone		Osteoporosis treatment commenced and stable.	Required shared care pathway with ICS to reduce the list of patients and smoothen the flow out from department
Reproductive	**Confirmed and treated** hypogonadism. PCOS.	Confirmed, treated and stable hypogonadism.	Required shared care pathway with

	Hirsutisms. Hypothalamic amenorrhoea. Other conditions suitable.		ICS to reduce the list of patients and smoothen the flow out from department
Miscellaneous	Any other referrals example: Reactive hypoglycaemia referred to dietician and stable.	Any other referrals example: Reactive hypoglycaemia referred to dietician, next line treatment commenced and stable.	Required shared care pathway with ICS to reduce the list of patients and smoothen the flow out from department

PIFU patient criteria check list for healthcare professionals.

Patient Name:……..
NHS No……..…Hospital No: ……
DOB: …… PIFU Check list date:……
Name and signature of Health care professional……..

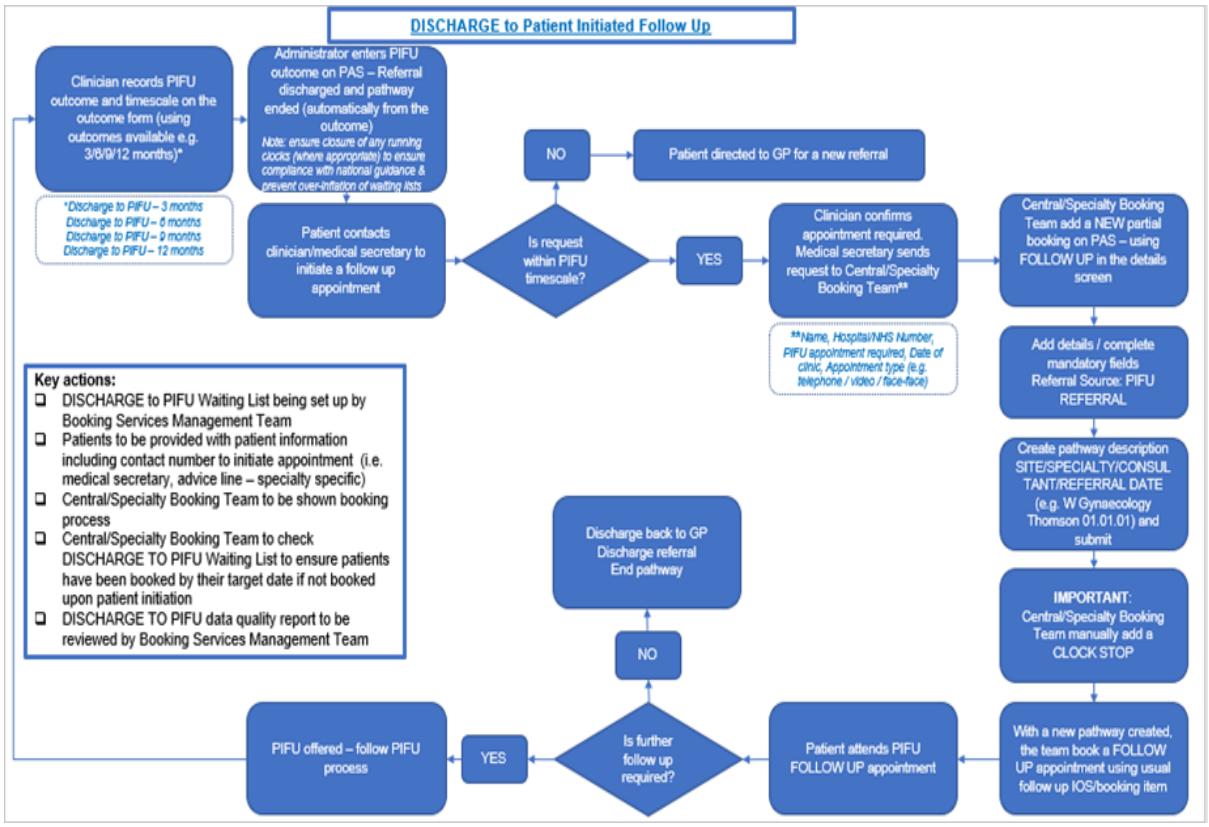
No	Check list	Yes	No	N/A	Sign	Comments
1.	Any safeguarding concerns.					
2.	Patient can access the service easily (Any poor accessibility to telephone or internet services)					
3.	Any complex health issues.					
4.	Confident and able to take responsibility for their care while on the PIFU pathway (do not have rapidly progressive dementia, severe memory loss or severe learning difficulty).					
5.	Have insight into changes in their symptoms and awareness of the indicators that might indicate need for service					
6.	Understand how to book follow-up appointments with the service and how long they will be responsible for this. (For some patients, this task may be carried out by administrative staff in their care home or GP.)					
7.	Is this patient being suitable for PFU pathway?					
8.	Explanation given about PIFU, and the pathway chosen.					
9.	PIFU Patient information booklet given and completed necessary part?					
10.	Allowed questions and any concerns for patient to raise					
11.	Patient is agreed and consented.					

Patient signature……Date……...
Health care professional signature……Date…….

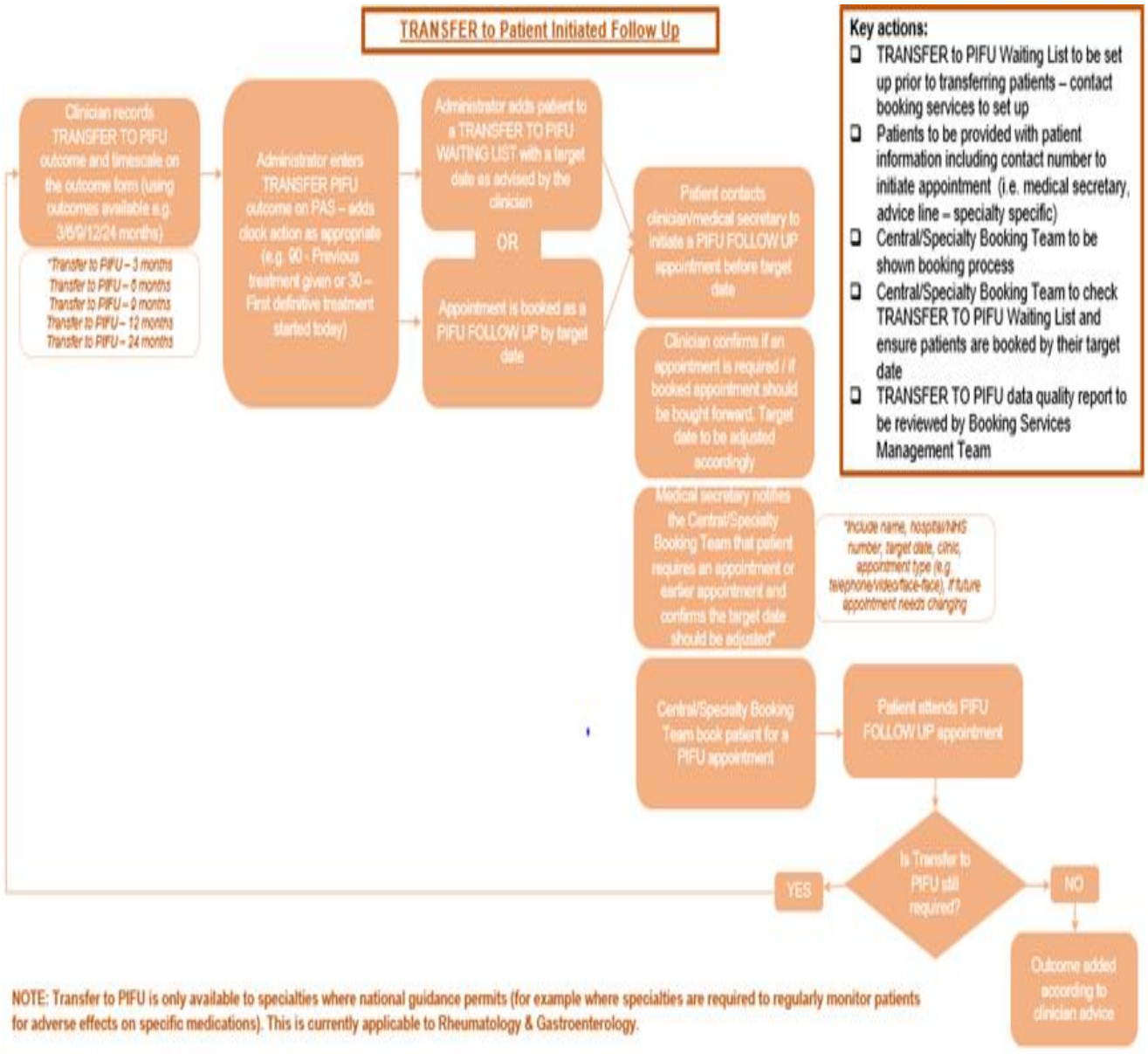
Virtual/remote clinics

Virtual and remote clinics are becoming increasingly common in endocrinology services. Patients receive invitations by secondary care for required monitoring tests and investigations. The results are processed by secondary care and patients will have a clinic appointment booked if results are abnormal, or they will receive written correspondence that the results were acceptable and what the next plan will be, including prompts to contact the service should they have any questions. This type of model could be used to supplement a patient's PIFU pathway by providing the system and process for required regular monitoring and regular communications to reduce the risk of patient hesitancy at making contact should they need to make a PIFU request.

PIFU Endocrine Patient Pathway – PIFU-Discharge pathway



PIFU Endocrine Patient Pathway – PIFU-Transfer



Risks

Review the document on mitigating risks when using PIFU which is available on NHS Futures.
Details some of the risks specific to endocrinology.

No	Risk	Proposed mitigations
1	Patients on a PIFU pathway may become hesitant in making contact. This could: • present a clinical risk because their condition is deteriorating without endocrinology services being aware. • increase the workload on GPs responding to patients' queries due to reduced formal follow up, which should be directed at the endocrinology service. • create a perceived inequality of access.	It is important that there is a shared decision with the patient on whether PIFU is right for them. Provision of information to patients to support personalised care in a format that meets their requirements. The information patients receive should clearly detail who the contact points are in secondary care and advise them to use this if their symptoms or circumstances change rather than attending their GP Establishing a regular reminder system, perhaps using email or text message, to remind patients on a PIFU pathway how to contact the endocrinology service Use contact for routine tests and investigations as an opportunity to remind patients how they can trigger a PIFU request
2	Due to no specified follow up appointment slot patients do not attend for the required test and investigation monitoring	A robust system is essential to ensure a record of: • written information given to patient about the importance of attending the planned tests/investigations • all required tests and investigations patients require • whether tests have been completed • the results of the tests and if action is required
3	Where follow up appointments perform a wider function than a discussion between the healthcare professional and patient, there is a risk these activities will not be undertaken if the patient is moved to a PIFU pathway or where responsibility lies for organising and interpreting these tests become less clear. Examples of additional activities undertaken at endocrinology follow up appointments include: • relevant monitoring tests and investigations • weight measurement • blood pressure measurements	Review suitability of patients for PIFU. If a follow up appointment performs many functions PIFU may not be suitable If a PIFU pathway is implemented, formal locally agreed plans will be required to ensure these activities are still undertaken and clear responsibility is designated. This may include PIFU being used alongside timed appointments. Plans should ensure the patient does not need to coordinate different clinical teams to access

	• interpretation and resulting action from tests and investigation results • replacing emergency injections kits and delivering refresher courses for patients on use	relevant test. The patient must be fully informed about: • where tests are to be done • when • how results will be fed back to endocrinology services
4	Patients are negatively impacted by a PIFU pathway due to them being within a protected characteristic group or being at risk of health inequalities	Use the Provider EHIA template as part of the PIFU service set up planning and to form the assessment criteria for suitability for PIFU.

Health inequalities

The National Outpatient Recovery and Transformation programme have developed a Provider EHIA template for local use. This should be used and acted upon as part of service planning to ensure patients are not disadvantaged by the PIFU pathway. This will help to better understand the potential positive and negative impacts of PIFU for patients and to identify effective interventions to address potential inequalities that could emerge. The specific endocrinology considerations below should be taken into account when implementing the Provider EHIA template within endocrinology outpatient services;

Protected characteristic group	**Endocrine specific considerations impacting on this group**
Age: older people; middle years; early years; children and young people.	• Endocrine conditions are more common in people as they age
Disability: physical, sensory and learning impairment; mental health condition; long-term conditions	• Endocrinology has quite a wide number of conditions which cause patients to identify with the disability protected characteristic group including: • Cushing's disease can cause depression, paranoia and psychosis and insulinoma can cause confusion and anxiety. • Phaeochromocytomas can cause severe anxiety. • Hyperparathyroidism can cause depression.

	• Hypogonadism and Addison's disease can cause problems with loss of energy in men and women. • Many endocrine conditions (including hypothyroidism and hyperthyroidism) are considered a long-term condition requiring long term monitoring and management. • Congenital endocrine conditions can affect learning.
Gender reassignment and/or people who identify as transgender	• Endocrine services will provide hormone expertise for some patients within this group
Marriage & civil partnership: people married or in a civil partnership	• None noted
Pregnancy and maternity: women before and after childbirth and who are breastfeeding.	• Several endocrine conditions can affect fertility. • Some endocrine conditions lead to increased risks during pregnancy and therefore additional management and monitoring during antenatal and postnatal care is needed.
Race and ethnicity (any ethic group that experiences inequalities)	• People of Black, Asian and other ethnic minority groups have increased risks associated with obesity at a lower BMI than people of White ethnicity • Prevalence of obesity is higher in people of Black ethnicity than in other ethnic groups
Religion and belief: people with different religions/faiths or beliefs, or none.	• None noted
Sex: men; women	• Endocrine conditions are more common in women than men • Men and women can be diagnosed with congenital adrenal hyperplasia. It effects production of male sex hormones creating physical changes in the patient.

Sexual orientation: Lesbian; Gay; Bisexual; Heterosexual	• None noted
Groups at risk of health inequalities	Endocrine specific considerations impacting on this group
Carers of patients: unpaid, family members	• People with complex or more severe endocrine conditions may need to travel to specialist centres, which may be distant from where they live. Carers may not be able to attend if respite care cannot be organised and funded.
Homeless people. People on the street; staying temporarily with friends/family; in hostels or B&Bs	• Most endocrine conditions require regular medications and monitoring (ie blood tests), concordance with these may be more challenging people in these situations.
People involved in the criminal justice system: offenders in prison/on probation, ex-offenders.	• Most endocrine conditions require regular medications and monitoring (ie blood tests), concordance with these may be more challenging people in these situations.
People with addictions and/or substance misuse issues	• None noted
People or families on a low income	• Prevalence of obesity is higher in people with lower socioeconomic status. There may be issues with food poverty limiting food choices. • People with complex or more severe endocrine conditions may need to travel to specialist centres, which may be distant from where they live and they may not have the means to pay for the travel, be able to take time off work or will lose income (eg self-employed/zero hour contract) by attending an appointment.

People with poor literacy or health Literacy: (eg poor understanding of health services poor language skills).	• The mechanisms of hormonal control are complex and may be difficult for people with poor literacy or health literacy to understand well.
People living in deprived areas	• Prevalence of obesity is higher in people with lower socioeconomic status. There may not be safe/suitable areas for physical activity or suitable cooking facilities and access to healthy food options may be challenging.
People living in remote, rural and island locations	• Some patients with complex endocrine conditions may require services only available in specialist centres which may be a long distance from where they live
Refugees, asylum seekers or those experiencing modern slavery	• None noted
People with little or no proficiency in English language	• The mechanisms of hormonal control are complex and can be difficult for people to understand well, especially for those with little English
People facing digital exclusion - those without digital equipment and reliable connectivity or have little knowledge of the use of or prefer not to use technology	• None noted

Gypsies, Romany Travellers	• Most endocrine conditions require regular medications and monitoring (ie blood tests), concordance with these may be more challenging for gypsies and travellers.
People living with domestic abuse: eg partner abuse, ex-partner abuse, family abuse.	• None noted
People facing social isolation	• None noted

Evaluating PIFU in endocrinology services

The Implementing patient-initiated follow-up guidance for local health and care systems presents relevant data collection methods for PIFU.

PIFU Endocrinology services plan evaluation based on the below:

Time	Evaluation Activity
3 months into implementation	• Number of patients moved onto a PIFU pathway each week • Total number of patients on a PIFU pathway • Number of patients who have initiated an appointment, and their feedback • Clinical experience and feedback • Administrative staff experience and feedback • Patient experience and feedback • Estimate future demand on administrative services eg due to booking follow up appointments • Review of any significant event or near misses
9 to 12 months into implementation	As above with: • Estimation of proportion of patients in the service that PIFU could be used with • Potential impact on demand for services • Safety review (significant events or near misses)

Monitoring

Page/ Section of Key Document	Key control:	Checks to be carried out to confirm compliance with the Policy:	How often the check will be carried out:	Responsible for carrying out the check:	Results of check reported to: *(Responsible for also ensuring actions are developed to address any areas of non-compliance)*	Frequency of reporting:
	WHAT?	**HOW?**	**WHEN?**	**WHO?**	**WHERE?**	**WHEN?**
	These are the 'key' parts of the process that we are relying on to manage risk. We may not be able to monitor every part of the process, but we MUST monitor the key elements, otherwise we won't know whether we are keeping patients, visitors and/or staff safe.	What are we going to do to make sure the key parts of the process we have identified are being followed? (Some techniques to consider are; audits, spot-checks, analysis of incident trends, monitoring of attendance at training.)	Be realistic. Set achievable frequencies. Use terms such as '10 times a year' instead of 'monthly'.	Who is responsible for the check? Is it listed in the 'duties' section of the Policy? Is it in the job description?	Who will receive the monitoring results? Where this is a committee the committee's specific responsibility for monitoring the process must be described within its terms of reference.	Use terms such as '10 times a year' instead of 'monthly'.

References

[You should include external source documents and other Trust documents that are related to this Policy]

Contribution List

Contribution List

This key document has been circulated to the following individuals for consultation;

Designation
Dr Ramalingam Bhaskar (Consultant)
Dr Mohammad Abdus Salam (Consultant)
Dr Divya Garg (Consultant)
Swapna George (Endocrine Specialist Nurse)
Dr Irfan Babar (Consultant)
Dr Munir Babar (Consultant)
Dr Ayesha Khalil (Consultant)
Alison Hall (Lead Nurse- Diabetes)

This key document has been circulated to the chair(s) of the following committee's / groups for comments;

Committee
Diabetes and endocrine directorate team.

Supporting Document 1 - Equality Impact Assessment Tool

To be completed by the key document author and included as an appendix to key document when submitted to the appropriate committee for consideration and approval.

Please complete assessment form on next page;

Herefordshire & Worcestershire STP - Equality Impact Assessment (EIA) Form
Please read EIA guidelines when completing this form

Section 1 - Name of Organisation (please tick)

Herefordshire & Worcestershire STP		Herefordshire Council		Herefordshire CCG	
Worcestershire Acute Hospitals NHS Trust	×	Worcestershire County Council		Worcestershire CCGs	
Worcestershire Health and Care NHS Trust		Wye Valley NHS Trust		Other (please state)	

Name of Lead for Activity	**Dr Ramalingam Bhaskar**

Details of individuals completing this assessment	**Name**	**Job title**	**e-mail contact**
	Dr Ramalingam Bhaskar	**Endocrinologist**	**ramalingam.bhaskar@nhs.net**
	Swapna George	**Endocrine Specialist Nurse**	**wah-tr.endocrinespecialistnurses@nhs.net**
	Endocrine team		**wah-tr.diabetesandendocrinereferrals@nhs.net**
Date assessment completed	**03/05/2024**		

Section 2

Activity being assessed (e.g. policy/procedure, document, service redesign, policy, strategy etc.)	**Title: Patient Initiated Follow-up (PIFU) Endocrinology**			
What is the aim, purpose and/or intended outcomes of this Activity?	Safe PIFU clinics and patient safety on PIFU pathway patients.			
Who will be affected by the development & implementation of this activity?	❑ × × ❑	Service User Patient Carers Visitors	× × ❑ ❑	Staff Communities Other _____

Is this:	❑ Review of an existing activity ×New activity ❑ Planning to withdraw or reduce a service, activity or presence?
What information and evidence have you reviewed to help inform this assessment? (Please name sources, eg demographic information for patients / services / staff groups affected, complaints etc.	• GIRFT Endocrinology. • Society of endocrinology UK PIFU Endocrinology guideline - DRAFT Guide to implementing patient initiated follow-up (PIFU) in endocrinology services 19 July 2022 • Clinically-led Endocrinology Outpatient Guidance Practical OPD guidance for endocrinology services to maximise efficiency and reduce waiting times for patients. NHS England 2023. • SOP
Summary of engagement or consultation undertaken (e.g. who and how have you engaged with, or why do you believe this is not required)	N/A
Summary of relevant findings	

Section 3

Please consider the potential impact of this activity (during development & implementation) on each of the equality groups outlined below. **Please tick one or more impact box below for each Equality Group and explain your rationale**. Please note it is possible for the potential impact to be both positive and negative within the same equality group and this should be recorded. Remember to consider the impact on e.g. staff, public, patients, carers etc. in these equality groups.

Equality Group	Potential positive impact	Potential neutral impact	Potential negative impact	Please explain your reasons for any potential positive, neutral or negative impact identified
Age		×		Endocrine conditions are more common in people as they age.
Disability		×		Endocrinology has quite a wide number of conditions which cause patients to identify with the disability protected characteristic group including: • Cushing's disease can cause depression, paranoia and psychosis and insulinoma can cause confusion and anxiety. • Phaeochromocytomas can cause severe anxiety. • Hyperparathyroidism can cause depression. • Hypogonadism and Addison's disease can cause problems with loss of energy in men and women. • Many endocrine conditions (including hypothyroidism and hyperthyroidism) are

Equality Group	Potential positive impact	Potential neutral impact	Potential negative impact	Please explain your reasons for any potential positive, neutral or negative impact identified
				considered a long-term condition requiring long term monitoring and management. • Congenital endocrine conditions can affect learning.
Gender Reassignment		×		• Endocrine services will provide hormone expertise for some patients within this group.
Marriage & Civil Partnerships		×		None noted. This policy will have neutral impact on all equality groups.
Pregnancy & Maternity		×		• Several endocrine conditions can affect fertility. • Some endocrine conditions lead to increased risks during pregnancy and therefore additional management and monitoring during antenatal and postnatal care is needed.
Race including Traveling Communities		×		None noted. This policy will have neutral impact on all equality groups. Travelling Communities: • Most endocrine conditions require regular medications and monitoring (ie blood tests), concordance with these may be more challenging for gypsies and travellers.
Religion & Belief		×		None noted. This policy will have neutral impact on all equality groups.
Sex		×		• Endocrine conditions are more common in women than men • Men and women can be diagnosed with congenital adrenal hyperplasia. It effects production of male sex hormones creating physical changes in the patient.
Sexual Orientation		×		None noted. This policy will have neutral impact on all equality groups.
Other Vulnerable and Disadvantaged Groups (e.g. carers;		×		**Carers of patients: unpaid, family members** • People with complex or more severe endocrine conditions may need to travel to specialist centres, which may be distant from

Equality Group	Potential positive impact	Potential neutral impact	Potential negative impact	Please explain your reasons for any potential positive, neutral or negative impact identified
care leavers; homeless; Social/Economic deprivation, travelling communities etc.)				where they live. Carers may not be able to attend if respite care cannot be organised and funded. **Homeless people.** People on the street; staying temporarily with friends/family; in hostels or B&Bs • Most endocrine conditions require regular medications and monitoring (ie blood tests), concordance with these may be more challenging people in these situations. **People involved in the criminal justice system:** offenders in prison/on probation, ex-offenders. • Most endocrine conditions require regular medications and monitoring (ie blood tests), concordance with these may be more challenging people in these situations.
Health Inequalities (any preventable, unfair & unjust differences in health status between groups, populations or individuals that arise from the unequal distribution of social, environmental & economic conditions within societies)		×		Endocrine specific considerations impacting on this group. **People or families on a low income** • Prevalence of obesity is higher in people with lower socioeconomic status. There may be issues with food poverty limiting food choices. • People with complex or more severe endocrine conditions may need to travel to specialist centres, which may be distant from where they live and they may not have the means to pay for the travel, be able to take time off work or will lose income (eg self-employed/zero hour contract) by attending an appointment. **People with poor literacy or health Literacy**: (eg poor understanding of health services poor language skills). • The mechanisms of hormonal control are complex and may be difficult for people with poor literacy or health literacy to understand well. **People living in deprived areas**. • Prevalence of obesity is higher in people with lower socioeconomic status. There may not be safe/suitable areas for physical activity or suitable cooking facilities and access to healthy food options may be challenging.

Equality Group	Potential positive impact	Potential neutral impact	Potential negative impact	Please explain your reasons for any potential positive, neutral or negative impact identified

Section 4

What actions will you take to mitigate any potential negative impacts?	Risk identified	Actions required to reduce / eliminate negative impact	Who will lead on the action?	Timeframe
	None.	PIFU patient criteria check list for healthcare professionals included in guideline, please see page 14. Patient information booklet for Endocrinology PIFU available.	Endocrine team	
How will you monitor these actions?				
When will you review this EIA? (e.g in a service redesign, this EIA should be revisited regularly throughout the design & implementation)				

Section 5 - Please read and agree to the following Equality Statement

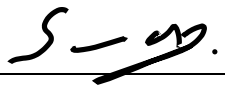
1. Equality Statement

1.1. All public bodies have a statutory duty under the Equality Act 2010 to set out arrangements to assess and consult on how their policies and functions impact on the 9 protected characteristics: Age; Disability; Gender Reassignment; Marriage & Civil Partnership; Pregnancy & Maternity; Race; Religion & Belief; Sex; Sexual Orientation

1.2. Our Organisations will challenge discrimination, promote equality, respect human rights, and aims to design and implement services, policies and measures that meet the diverse needs of our service, and population, ensuring that none are placed at a disadvantage over others.

1.3. All staff are expected to deliver services and provide services and care in a manner which respects the individuality of service users, patients, carer's etc, and as such treat

them and members of the workforce respectfully, paying due regard to the 9 protected characteristics.

Signature of person completing EIA	Swapna George 
Date signed	03/05/2024
Comments:	Endocrine Specialist Nurse.
Signature of person the Leader Person for this activity	Dr Ramalingam Bhaskar 
Date signed	03/05/2024
Comments:	Endocrine consultant

Supporting Document 2 – Financial Impact Assessment

To be completed by the key document author and attached to key document when submitted to the appropriate committee for consideration and approval.

	Title of document:	Yes/No
1.	Does the implementation of this document require any additional Capital resources	No
2.	Does the implementation of this document require additional revenue	No
3.	Does the implementation of this document require additional manpower	No
4.	Does the implementation of this document release any manpower costs through a change in practice	Yes
5.	Are there additional staff training costs associated with implementing this document which cannot be delivered through current training programmes or allocated training times for staff	No
	Other comments:	

If the response to any of the above is yes, please complete a business case and which is signed by your Finance Manager and Directorate Manager for consideration by the Accountable Director before progressing to the relevant committee for approval.