Reference Number: **Version Number: 1.1**	**Date of Next Review: 24/7/2023** **Previous Trust/LHB Reference Number:**

Title: Patient Initiated Follow up in Endometrial Cancer

Introduction and Aim:
This guideline has been written following a recent (2020) publication issued by the British Gynaecological Cancer Society (BGSC) on patient initiated follow up (PIFU) in gynaecological malignancies. PIFU means that a patient ceases to have routine follow-up appointments in the hospital and are instructed to contact the service should they experience symptoms that could indicated recurrent disease.This guideline specifically outlines an appropriate approach to this form of follow-up in cases of endometrial cancer and has been written to bring our department in line with national guidance. There is no evidence available to identify the optimum follow-up in patients following treatment of endometrial cancer in terms of early detection of recurrent disease. The benefit of this mode of follow up for the patient is less clinic appointments which are often associated with anxiety, discomfort of examination and the practical problems including taking time off work, care for dependents and parking etc. The benefits of the healthcare provided include reduced clinic appointments taking pressure off the service whilst not compromising the individual.

Objectives

- **To implement PIFU in eligible women following treatment of early stage endometrial cancer**

Scope
This policy applies to all healthcare professionals in all locations including those with honorary contracts

Equality Health Impact Assessment	*An Equality Health Impact Assessment (EHIA) has not been completed.*
Documents to read alongside this Procedure	*Newton C, Nordic A, Rolland P et al. British Gynaecological Cancer Society recommendations and guidance on patient initiated follow-up (PIFU). Int J Gynaecological Cancer. 2020. Doi: 10.1136/IJGC-2019-001176* *https://www.bgcs.org.uk/wp-content/uploads/2020/04/IJGC-British-Gynaecological-Cancer-Society-recommendations-and-guidance-on-patient-initiated-follow-up-PIFU.pdf*
Approved by	*Gynaecology Professional Forum*

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Summary of reviews/amendments			
Version Number	**Date of Review Approved**	**Date Published**	**Summary of Amendments**

Important: *These guidelines have primarily been devised from the BGCS Recommendations and guidance on patient-initiated follow-up (PIFU) with the addition of flow charts in the appendix designed to facilitate implementation. The full BGCS guideline can be found at the following link:*

https://www.bgcs.org.uk/wp-content/uploads/2020/04/IJGC-British-Gynaecological-Cancer-Society-recommendations-and-guidance-on-patient-initiated-follow-up-PIFU.pdf

Background

Patient-Initiated Follow-Up (PIFU)

The British Gynaecological Cancer Society (BGCS) has issued a number of guidelines to improve the quality of care and standardise treatment and follow up pathways for gynaecological cancer patients. As the practice of to follow up varies widely[1] and is continuously evolving, the BGCS wishes to implement strategies for a UK-wide implementation for patient-initiated-follow-up (PIFU), addressing its indications, value, and limitation across all different gynaecological cancer sites. The National Cancer Survivorship Initiative, through National Health Service (NHS) improvement has already implemented stratified pathways (including some patient initiated) for follow-up in breast, colorectal and prostate cancer[2]. Patients with early stage cancer of the breast, colorectal and prostate maybe offered remote surveillance, but at the present time no surveillance techniques have been deemed to be effective in gynaecological cancers.

Historically, patients have been kept on hospital-based follow-up in dedicated outpatients clinics for 5-10 years following diagnosis and treatment in Gynaecological cancer[3,4]. The main aims of follow-up include: detection of asymptomatic recurrences, with the assumption that this will improve prognosis; detection and management of side effects of treatment; improvement in quality of life; and identification and treatment of patients concerns and anxieties around their cancer diagnosis[5,6]. However, there is no evidence that intensive follow-up improves survival[7-13] and women often find clinical examination uncomfortable (especially vaginal examination), with 54% (48/89) experiencing increased anxiety before their follow-up appointment[6].

There is evidence that the current hospital-based follow-up does not necessarily meet cancer survivors needs, failing to provide emotional support and information needs[14] due to limited time, resources and lack of focus on a holistic approach of the patients needs. A holistic approach will take account of mental and social factors as well as symptoms of the disease. In 2010 the National Cancer Survivorship Initiative (NCSI) was launched by the Department Of Health in England in collaboration with one of the UK's largest charitable organisations, Macmillan Cancer Support, to improve the long term consequences of surviving cancer[15]. In more recent years, the Living With and Beyond Cancer program[16] has advocated a shift in care and support towards self-management, based on individual needs and preferences, and away from the traditional single model of clinical follow-up. This approach empowers individuals to take responsibility for their condition, supported by clinical assessment to enable early recognition of symptoms of recurrence or consequences of their treatment, and a 'recovery package' that includes holistic needs assessments (performed after completion of treatment for cancer), treatment summaries, health and well-being events and cancer care reviews in primary care[16].

There are different follow-up methods currently utilised in the UK which include hospital follow-up, telephone follow-up and PIFU. Hospital follow-up involves seeing patients in clinical at regular intervals, whereas telephone follow-up involved calling patients at a specified time at a pre-determined intervals. PIFU involves educating patients about concerning symptoms, such as vaginal bleeding, unintentional weight loss and worsening abdominal pain or bowel/bladder symptoms. In PIFU, patients are not given routine follow up appointments (hospital, telephone or with general practitioner), but instead are empowered to call the gynaecological oncology team directly (often via the clinical nurse specialist with specialist cancer knowledge) if they have these symptoms, and then they are fast-tracked back into a specialist care system. It is very important that patients are given written information about PIFU, which includes the contact details should they need them. Most patients find PIFU acceptable[17], although younger patients those who struggle to access healthcare (due to socio-demographic factors) may require the additional support[18] of routine contact, either via hospital follow-up or telephone follow-up.

PIFU in Endometrial Cancer

There are approximately 9300 new cases of endometrial cancer in the UK (2019) and it is the fourth most common cancer in women[20]. There has been an increase of nearly 20% in the

last 10 years[20], which is thought to be largely due to the sharp increase in obesity, although rarer tumours, not associated with obesity have also increased.

Low risk endometrial cancer is defined by the European Society of Medical Oncology-European Society of Gynaecological Oncology (ESMO-ESGO) guidelines[21] as stage 1 of endometrioid, grade 1-2 histology, with <50% myometrial invasion, negative for lymph vascular space invasion, and hence not in need of adjuvant treatment[21]. Following hysterectomy and bilateral salpingo-oophrectomy, patients have their holistic needs assessment and the next steps of their journey discussed with their dedicated cancer support workers, under the coordination and guidance of the clinical nurse specialists. They can also be referred to psycho-oncological counselling services, if required and accepted by the patient. Patients are educated about symptoms that would be concerning for a recurrence, such as vaginal bleeding, worsening or persistent abdominal pain, or bladder/bowel symptoms. A population study by Salvesen over 10 years demonstrated that 653 patient consultations were needed to pick up one asymptomatic low-risk endometrial cancer patient with recurrent disease[13,14]. Based on a very-low risk of relapse without adjuvant treatment, these patients could be offered PIFU after they have completed treatment at, or shortly after, the time of their holistic needs assessment appointment (Table 1 and Appendix: Flow Chart 1).

Table 1 Guidelines for follow-up in endometrial cancer

Endometrial cancer	Clinic-based follow-up	Telephone follow-up ± blood test	PIFU
Low risk (<10% ROR)	If patient declines PIFU (for maximum of 2 years from end of treatment)	If patient declines PIFU (for maximum of 2 years from end of treatment)	Offer from end of treatment (after holistic needs assessment at 3 months)
Intermediate risk	Can be offered if patient declines PIFU for 2 years from end of treatment	Can be offered if patient declines PIFU for 2 years from end of treatment	Offer from end of treatment or after 2 years for all
High-intermediate risk	For 5 years (either telephone follow-up or clinic follow-up)	For 5 years (either telephone follow-up or clinic follow-up)	Offer from 2 years from end of treatment in place of telephone follow-up or clinic follow-up
High risk	For 5 years (either telephone follow-up or clinic follow-up)	For 5 years (either telephone follow-up or clinic follow-up)	Offer from 2 years from end of treatment in place of telephone follow-up or clinic follow-up

PIFU, patient-initiated follow-up; ROR, risk of recurrence.

Intermediate risk endometrial cancer is defined by the ESMO-ESGO guidelines[21] as stage 1 endometrioid, grade 1-2, >50% myometrial invasion, and lymphoma secular space invasion negative. These patients are commonly offered vaginal brachytherapy, without external

beam radiotherapy, following their hysterectomy [21]. Their risk of recurrence is relatively low. Patients could be offered PIFU at the 3 month review after treatment or anytime during the first 2 years of hospital follow-up. It is important for patients to be aware that they may develop late onset toxicity following brachytherapy that may not be apparent shortly after finishing their treatment. For that reason, it should be explained that they can be seen back in clinic, if they have concerns related to toxicity, as well as if they have symptoms concerning for recurrence, if they are on PIFU. Another option for these patients is telephone follow-up with randomised controlled trial-level data of no physical or psychological detriment, compared with hospital follow-up, in stage 1 endometrial cancer[22]. Telephone follow-up could be seen as a useful transition between face-to-face hospital-based appointments and PIFU (Appendix: Flow Chart 2).

High-intermediate risk endometrial cancer is defined by the ESMO-ESGO guidelines[21] as patients with grade 1-2 tumours with deep (>50%) myometrial invasion and unequivocally positive (substantial, not focal) lymphovascular space invasion, and those with grade 3 tumours with <50% myometrial invasion regardless of lymphovascular space invasion status. These patients are treated as high-risk for the purpose of these guidelines, due to their higher risk of recurrent disease. High-intermediate risk endometrial cancer represents a heterogeneous group of patients including both endometrioid and non-endometrioid tumour types, such as serous and clear cell, and ranges from stage 1b grade 3 (with or without nodal staging) to more advanced International Federation of Gynaecology of Obstetrics (FIGO) stages[21]. The risk of recurrence is higher for these patients (>20%)[23] and therefore it is suggested that they should be seen in the clinic for at least the first 2 years[24], as this is the most frequent time for recurrence. After 2 years patients could be offered PIFU for the remaining 3 years. Again another alternative is telephone follow-up for the remaining 3 years (Appendix: Flow Chart 3).

Eligibility Criteria for PIFU:

1.	Patient willing
2.	Should not have recurrent disease
3.	Not in a clinical trial where follow-up protocol exists
4.	Be able to communicate concerns without significant language barrier or psychological co-morbidity and have competence to agree to follow-up arrangements

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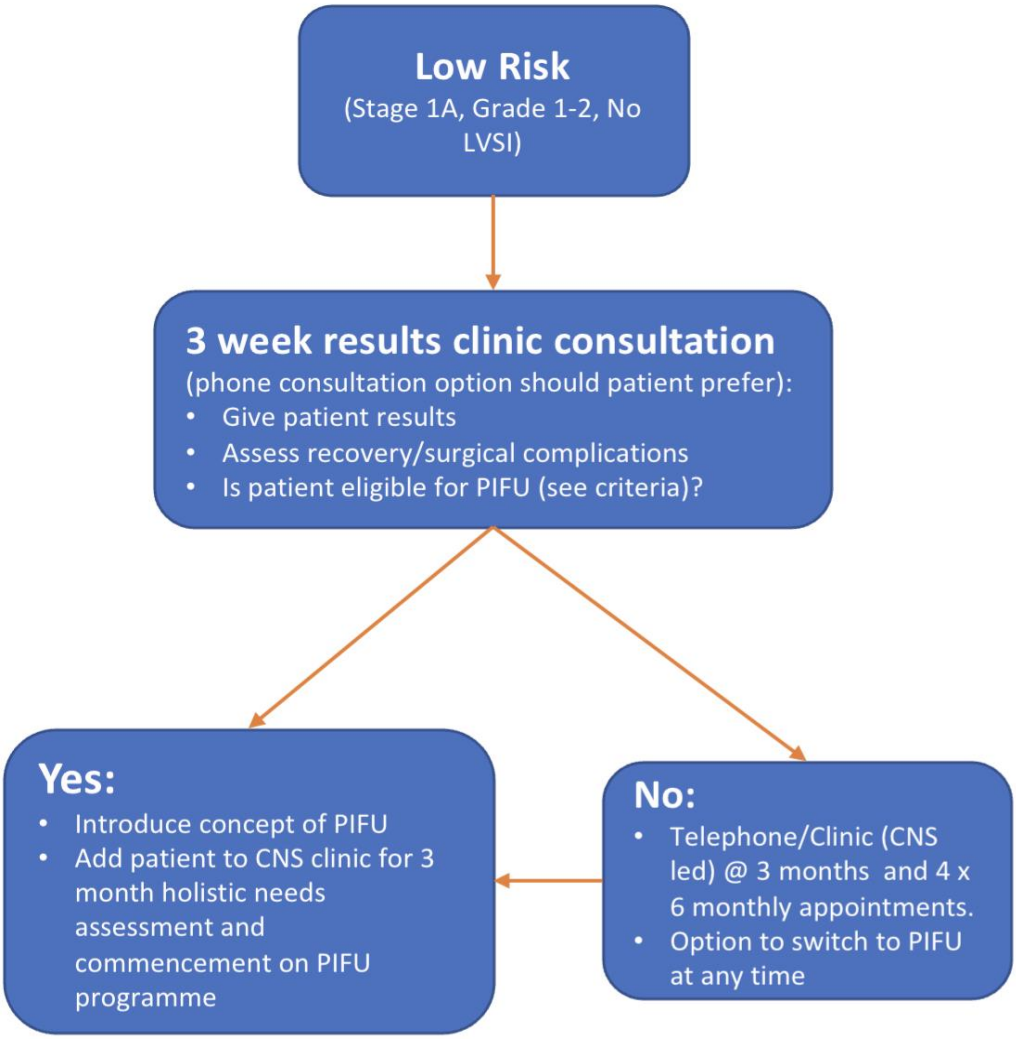
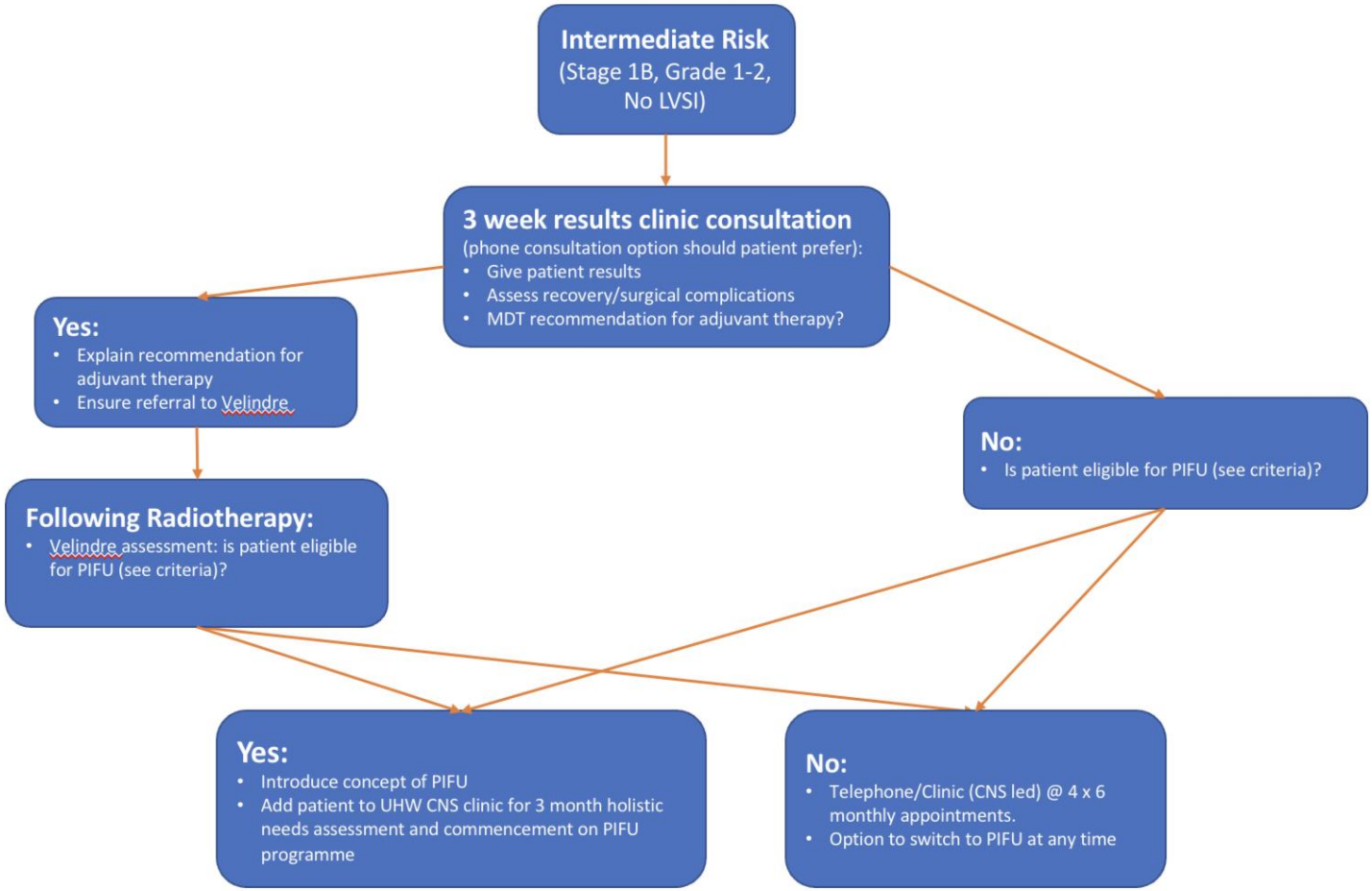
Appendix

Flow Chart 1: Low Risk Endometrial Cancer



Flow Chart 2: Intermediate Risk Endometrial Cancer



Flow Chart 3:

High-Intermediate Risk and High Risk Endometrial Cancer