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British Gynaecological Cancer Society recommendations and guidance on patient-initiated follow-up (PIFU)

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ABSTRACT

The National Cancer Survivorship Initiative through the National Health Service (NHS) improvement in the UK started the implementation of stratified pathways of patient-initiated follow-up (PIFU) across various tumor types. Now the initiative is continued through the Living With and Beyond Cancer program by NHS England. Evidence from non-randomized studies and systematic reviews does not demonstrate a survival advantage to the long-established practice of hospital-based follow-up regimens, traditionally over 5 years. Evidence shows that patient needs are inadequately met under the traditional follow-up programs and there is therefore an urgent need to adapt pathways to the needs of patients. The assumption that hospital-based follow-up is able to detect cancer recurrences early and hence improve patient prognosis has not been validated. A recent survey demonstrates that follow-up practice across the UK varies widely, with telephone follow-up clinics, nurse-led clinics and PIFU becoming increasingly common. There are currently no completed randomized controlled trials in PIFU in gynecological malignancies, although there is a drive towards implementing PIFU. PIFU aims to individualize patient care, based on risk of recurrence and holistic needs, and optimizing resources. The British Gynaecological Cancer Society wishes to provide the gynecological oncology community with guidance and a recommendations statement regarding the value, indications, and limitations of PIFU in endometrial, cervical, ovarian, and vulvar cancers in an effort to standardize practice and improve patient care.

INTRODUCTION

The British Gynaecological Cancer Society (BGCS) has issued a number of guidelines to improve the quality of care and standardize treatment and follow-up pathways for gynecological cancer patients. As the practice of follow-up varies widely[1] and is continuously evolving, the BGCS wishes to implement strategies for a UK-wide implementation of patient-initiated follow-up (PIFU), addressing its indications, value, and limitations across all different gynecological 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 may be offered remote surveillance, and at the present time no surveillance techniques have been deemed to be effective in gynecological cancers.

Historically, patients have been kept on hospital-based follow-up in dedicated outpatient clinics for 5–10 years following diagnosis and treatment for gynecological 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 patient 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 organizations, 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 utilized in the UK which include hospital follow-up, telephone follow-up, and PIFU. Hospital follow-up involves seeing patients in clinics at regular intervals, whereas telephone follow-up involves calling patients at a specified time at 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 a general practitioner), but instead are empowered to call the gynecological 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 the 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 and 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.

METHODS

The BGCS PIFU meeting was held on March 14, 2019 in London, UK. Experts from clinical practice (including medicine and nursing) and academia, with specialist knowledge and expertise in gynecological oncology and alternative follow-up strategies, reviewed available evidence from a systematic literature search in Medline, Embase CINAHL, AMED, BNI, HBE, HMIC, and PsycINFO that aimed to identify significant evidence on alternatives to hospital-based follow-up. These data were presented, discussed, and evaluated by the key opinion leaders. Additionally, data from a national survey of follow-up practice across the UK in gynecological malignancies were presented. All experts agreed the consensus guidelines for each gynecological tumor site (cervical, ovarian, endometrial, and vulval).

Although there was no patient representative at the BGCS PIFU meeting, there has been positive feedback from patients within the hospitals that have already implemented the guidelines and in studies which looked at patient acceptability.[17–19]

Disclaimer

Clinicians should always use their clinical judgment to determine if an individual patient is suitable for PIFU. These consensus recommendations have been produced as guidance for follow-up pathways and are based on available evidence. Where little evidence existed, expert consensus was agreed.

RESULTS

PIFU guidance for each cancer type will be presented separately under the general umbrella and recommendation that only those patients who fit all of the criteria below are eligible and safe to be offered PIFU.

General eligibility criteria for patient-initiated follow-up (PIFU)

- Completed primary treatment for a gynecological malignancy and are clinically well
- Patients should be willing and able to access healthcare if on PIFU
- They should be without significant treatment related side-effects that need ongoing management
- They should not have recurrent disease
- They should not be on active or maintenance treatment
- They should not be on a clinical trial where follow-up schemes are defined and limited to hospital-based follow-up
- They should not have a rare tumor with uncertain risk of recurrence and need for ongoing management
- They must be able to communicate their concerns without a significant language barrier or psychological co-morbidity and have competence to agree to PIFU

At the clinic visit before offering PIFU, patients should be provided with a careful explanation on the lack of evidence for benefit from regular follow-up visits to the hospital and the rationale for implementing a supported self-management approach (PIFU). However, for patients with significant iatrogenic side effects, which impair their quality of life and need active management, it is important that those are addressed and managed within the clinic setting with sufficient access to other health professionals, such as gastroenterologists, urologists, endocrinologists, and psychologists. PIFU should be offered on a case-by-case basis, ensuring there are no existing unmet needs and according to their cancer type.

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 tumors not associated with obesity have also increased.

Low risk endometrial cancer is defined by the European Society of Medical Oncology- European Society of Gynecological Oncology (ESMO-ESGO) guidelines[21] as stage 1 of endometrioid, grade 1–2 histology, with ≤50% myometrial invasion, negative for lymphovascular space invasion, and hence not in need of adjuvant treatment.[21] Following hysterectomy and bilateral salpingo-oopherectomy, 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 counseling 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).

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 I endometrioid, grade 1–2, ≥50% myometrial invasion, and lymphovascular 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 randomized 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.

High-intermediate risk endometrial cancer is defined by the ESMO-ESGO guidelines[21] as patients with grade 1–2 tumors with deep (≥50%) myometrial invasion and unequivocally positive (substantial, not focal) lymphovascular space invasion, and those with grade 3 tumors 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 tumor types, such as serous and clear cell, and ranges from stage IB grade 3 (with or without lymphovascular space invasion and with or without nodal staging) to more advanced International Federation of Gynecology and 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 (Table 1). Again, another alternative is telephone follow-up for the remaining 3 years.

Cervical Cancer

There are approximately 3200 new cases of cervical cancer every year[25] with an incidence of 12 per 100 000 in the UK.[25]

Patients who have undergone fertility-sparing treatment for cervical cancer, such as trachelectomy or large loop excision of transformation zone (LLETZ)/cone biopsy should be excluded from PIFU, due to the necessity of regular colposcopic examinations ± cervical screening after fertility-sparing surgery.[26] ESGO guidelines recommend that patients who have had a radical trachelectomy for a stage 1B1 cervical cancer should be seen 3–4 monthly in the 2 years, then every 6–12 months until 5 years after treatment.[27] Human papillomavirus testing, with or without cytology, should be taken at each follow-up visit.[27] This is usually undertaken by a health professional, although a recent systematic review highlighted that human papillomavirus detection by self-sampling was just as accurate.[28] However, this has not been studied in a population after the diagnosis of cervical cancer and therefore cannot be recommended in this setting.

In patients with a FIGO stage 1A1 cervical cancer the British Society of Colposcopy and Cervical Pathology (BSCCP) recommend cervical cytology should be taken 6 and 12 months after treatment (hysterectomy or LLETZ) followed by annual cytology for a further 9 years, before returning to routine recall until the age of 65 for those treated with LLETZ and who still have a cervix.[27] If patients have had a hysterectomy for stage 1A1 cervical cancer there are specific guidelines on cytology follow-up depending on histology of the hysterectomy specimen.[27] Patients who have had a hysterectomy for stage 1A1 are also excluded from PIFU.

In low risk patients (FIGO stage 1B1) who have undergone a radical hysterectomy for treatment of cervical cancer the BGCS recommends follow-up in the clinic setting every 3–4 months in the first 2 years, and then PIFU can be offered (Table 2). It should be noted that the BSCCP recommends vault smears at 6 and 18 months after a hysterectomy for cervical intraepithelial neoplasia (CIN)[27] if margins are free of CIN. However, vaginal vault cytology should not be performed following treatment for ≥FIGO stage 1A2 as it does not add significantly to the detection of recurrent disease.[25 27 28] These patients have a 5 year risk of recurrence of

Table 2 Guidelines for follow-up in cervical cancer

Cervical cancer	Clinic-based follow-up	Telephone follow-up ± blood test	PIFU
Low risk (<10% ROR) excluding fertility sparing surgery/LLETZ	For 5 years post-completion of treatment	Not suitable	Offer from 2 years from end of treatment
Intermediate risk	For 5 years post-completion of treatment	Not suitable	Not suitable
High risk	For 5 years post-completion of treatment	Not suitable	Not suitable

LLETZ, large loop excision of transformation zone; PIFU, patient-initiated follow-up; ROR, risk of recurrence.

5.8–8%.[27 29–31] However, only 4–5% will have pelvic recurrences and only 1–2% can be salvaged,[28 31 32] although this has increased slightly with cyberknife and other techniques. In a large Danish national cohort study of 1523 patients with low risk cervical cancer, of those with a recurrent disease, 67.5% experienced a symptomatic recurrence[30] Other studies have shown similar rates of symptomatic recurrent cervical cancer.[24] Therefore, as the majority present with symptoms, PIFU appears to be reasonable for low risk patients. As surgery for early stage cervical cancer may cause morbidity, such as bladder dysfunction and lymphedema, hospital follow-up for the first 2 years was thought to be preferable to telephone follow-up (BGCS consensus agreement).

In patients with intermediate (risk of recurrence 10–20%) or high risk (risk of recurrence >20%) disease, hospital follow-up—to include taking an appropriate history and clinical examination at each visit—should be undertaken to try and detect recurrent disease. This group of patients usually have FIGO stage ≥1B2 although there are other factors that play a role in the likelihood of recurrence, such as lymph node status and lymphovascular space invasion.[30 33] Hospital follow-up should be undertaken for 5 years, particularly as these patients may have significant treatment-related toxicity (Table 2). However, it should be noted that the majority of recurrences occur within 2 years. A Norwegian national prospective observational study by Vistad et al in 2017, which included 680 patients with gynecological cancer recurrence, showed a mean annual incidence rate from years 3–5 of <7%.[30]

Ovarian Cancer

There were 7500 women who developed tubo-ovarian/primary peritoneal cancer in the UK in 2016, making it the sixth most common cancer in women.[34] The majority of those who developed tubo-ovarian/primary peritoneal cancer had epithelial ovarian cancer, which relates to these guidelines. Non-epithelial ovarian cancers, such as granulosa cell tumors or germ cell tumors of the ovary, are not included in these guidelines, as they have their own distinct pathogenesis and behave differently to epithelial ovarian cancer. Fertility-preserving surgery, that includes a unilateral salpingo-oophorectomy and full surgical staging, is acceptable in young patients with stage 1A (grade 1 and 2) and stage 1C (grade 1) disease, as they have similar recurrence rates and overall survival to those undergoing conventional treatment.[35] However, these patients should be seen regularly for hospital follow-up and ultrasound scans of the contralateral ovary and so are excluded from PIFU.

Only patients who have been adequately staged, with pelvic and para-aortic lymphadenectomy and peritoneal biopsies for an apparent stage 1 ovarian cancer, should be offered PIFU, so that occult higher stage cancers with higher risk of relapse are not included.[36] Patients with fully staged 1A/B ovarian cancer (of any grade) have a low risk of recurrence and therefore could be offered PIFU after they have completed their treatment (Table 3). Evidence does not suggest that routine follow-up of patients with ovarian cancer improves survival.[37–41] A randomized phase III study OV05-EORTC 55955,[40] which compared initiation of chemotherapy on development of elevated CA125 versus initiation of chemotherapy on clinical/symptomatic evidence of relapse, showed treatment was delayed by a median of 4.8 months in the latter group with no detriment to overall survival (HR 1.01, 95% CI 0.82 to 1.25; p=0.91). Moreover, quality of life was lower in the patients who had initiation of chemotherapy on CA125 rise. However, this study took place outside the possibility of secondary cytoreductive surgery for recurrent ovarian cancer, and also before the establishment of targeted and maintenance agents at relapsed disease, and it is unclear whether we can translate its findings to the modern era of ovarian cancer management.[36 42]

Table 3 Guidelines for follow-up in ovarian cancer

Ovarian cancer	Clinic-based follow-up	Telephone follow-up ± blood test	PIFU
Low risk (<10% ROR, stage 1A/B fully staged) from end of treatment (surgery ± chemotherapy). Excluding fertility sparing surgery	Can be offered if declines PIFU for 2 years from end of treatment	Can be offered if declines PIFU for 2 years from end of treatment	Offer from end of treatment (after holistic needs assessment at 3 months)
FIGO stages 1C–4	For 3 years from end of treatment	Can be offered for years 4-5 from end of treatment	Not suitable

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

Table 4 Guidelines for follow-up in vulval cancer

Options for follow-up	Vulval cancer
PIFU for 5 years from treatment	Not suitable
Remote/telephone ± bloods	Not suitable
Clinic-based follow-up	Follow-up including clinical inspection for at least 5 years from end of treatment

PIFU, patient initiated follow-up.

At the follow-up appointment, symptoms should be assessed and a physical examination should be carried out in the first 3 years from completing treatment in patients with FIGO stage 2–4, as this is the most common time period in which recurrent disease develops.[30] In years 4 and 5, in the absence of recurrent disease, patients could have the option of moving to a combination of telephone follow-up with CA125 serial measurements, if deemed suitable by their clinician. There is evidence that telephone follow-up in ovarian cancer is well received and the majority preferred it to hospital follow-up.[43] If patients are not suitable for telephone follow-up and remote CA125 measurements, patients should continue hospital follow-up for a minimum of 5 years after completing treatment.

Vulvar Cancer

Vulvar cancer is rare with only 1300 new cases in 2015 in the UK, which is <1% of all cancers in women.[44] Cancer of the vulvar primarily affects older women with the highest incidence of women aged 90 or over.[44] The difficulty of self-examination and the increased numbers of cases in deprived areas[44] lead to a greater number of vulnerable women. Therefore, the BGCS recommends that women with vulvar cancer are not suitable for PIFU (Table 4) and should follow the traditional follow-up schemes involving careful clinical examination. This should be performed by clinicians with appropriate experience, which would usually be in the hospital setting.

There is no evidence for the recommendations of frequency of examinations. The ESGO expert consensus guidelines and the Royal College of Obstetricians and Gynaecologists guidelines on vulvar cancer[45] recommend 3–4 monthly follow-up in the first 2 years, biannually for years 3 and 4, and then life-long follow-up. This is supported by a retrospective analysis of 330 patients with primary vulvar carcinoma treated at the Mayo Clinic, which showed 35% of recurrences occurred >5 years after diagnosis with both distant and local disease.[46] The BGCS recommends follow-up of patients with vulval cancer for at least 5 years, with longer follow-up at the discretion of the treating clinician. Patients with multi-focal vulvar intraepithelial neoplasia or lichen sclerosis with vulvar intraepithelial neoplasia (differentiated vulvar intraepithelial neoplasia) are at high risk of multi-focal disease and more intensive follow-up may be warranted.[45 47]

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