Worcestershire Acute Hospitals NHS Trust

Standard Operating Procedures

Patient Centred Follow Up (PCFU) for Gynaecological Cancer Patients

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Approved by:	**Gynaecology Governance**
Approved by Medicines Safety Committee: *Where medicines included in guideline*	**NA**
Date of Approval:	**10th June, 2022**
Date of Review: This is the most current document and is to be used until a revised version is available	**10th June, 2025**

Aim and scope of Standard Operating Procedure

Historically, patients have been kept on hospital-based follow-up in dedicated outpatient clinics for 5 years following diagnosis and treatment for a gynaecological cancer. 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. However, there is no evidence that intensive follow-up improves survival.

Women often find clinical examination uncomfortable (especially vaginal examination), with many experiencing increased anxiety before their follow-up appointment.
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 due to limited time, resources, and lack of focus on a holistic approach of the patients' needs. A holistic approach will take account of psychological and social factors as well as symptoms of the disease. (2)

Patient Centred Follow Up (PCFU) aims to empower patients to take responsibility for their own cancer. Supported by clinical assessment and education it will enable the patient to recognise early signs and symptoms of recurrence or consequences of their treatment. They will be offered a 'Recovery Package' that includes holistic needs assessments (performed after completion of treatment for cancer), treatment summary, health and well-being events, and cancer care reviews in primary care

PCFU is designed to deliver individualised patient care based on risk of recurrence, holistic needs assessment and optimising resources. Recent evidence indicates traditional 5 year follow-up regimes do not improve survival rates or reduce the risk of cancer recurrence. (1)

PCFU patients do not receive scheduled follow-up appointments (hospital, telephone or with a general practitioner), but instead are empowered to call the gynaecology cancer team directly via the clinical nurse specialist support helpline, if they have concerning symptoms. They are then fast-tracked back into the specialist care system.

Target Staff Categories

All

Key amendments to this Standard Operating Procedure

Date	Amendment	Approved by:
10th June, 2022	First document approved	Gynaecology Governance

Key messages

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 tumour 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 (2)

1. PCFU Definition

Patient Centred Follow Up: The follow-up pathway in which patients are empowered with the knowledge and skills to self-manage their condition. They are given information about the symptoms to look out for and who to contact if they notice any of these alert symptoms, future scheduled tests, and how to contact the specialist team if they have any concerns. They do not receive any further outpatient appointments unless further investigations or support is required.

2. Eligibility criteria

PCFU should be offered on a case-by-case basis, ensuring there are no existing unmet needs and according to the patient's cancer type**,** grade, stage, treatment and risk of recurrence. Future follow up should be documented clearly on the MDT outcome, including suitability for PCFU. The following eligibility criteria and BGCS guidelines must be taken into consideration when planning PCFU.

- Completed primary treatment for a gynaecological malignancy and are clinically well
- Patients should be willing and able to access healthcare if on PCFU
- 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 tumour 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 PCFU
- 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 PCFU, due to the necessity of regular colposcopic examinations.
- Suitable for discharge back to GP at the end of non-problematic follow up.

3. Informing the patient of their PCFU (Shared decision making)

The clinician should discuss PCFU with the patient at their end of treatment face to face appointment. 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 (PCFU). Most patients find PCFU acceptable, although some patients and those who struggle to access healthcare (due to socio-demographic factors) may require or prefer the additional support of routine contact, either via hospital follow-up or telephone follow-up.

For patients with significant post treatment 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 specialist health professionals.

At this point the patient should have their holistic needs assessment (HNA) and any outstanding issues addressed. The patient should be offered an end of treatment summary (SCR) specifying diagnosis, treatment and follow up plan and a copy sent to their GP. The next steps of the patient's journey will be 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.

4. Patient information

It is important that patients are given the appropriate verbal and written information (Appendix 1), explaining why they have been offered PCFU and the benefits they may expect. Patients should be given time to decide if they wish to consent to PCFU or remain in routine hospital follow up.
The patient information booklet gives information on how to recognise concerning symptoms such as vaginal bleeding, unintentional weight loss, worsening abdominal pain or bowel/ bladder symptoms, including contact details for the clinical nurse specialist helpline. It is important to ensure patients have the correct information to feel empowered and confident to be on PCFU. They can discuss returning to routine follow up at any time
Patients should also be given "Alert Cards" (Appendix 2) which are designed to fit into the patient's purse or wallet and should be given to every patient that has agreed to PCFU.

5. Key symptoms that should trigger a follow up request

- Sudden start of vaginal bleeding or vaginal discharge (offensive in smell or an unusual colour)
- Abdominal, pelvic or back discomfort that does not go away
- Abdominal swelling that steadily gets worse
- Change in bowel or bladder habits
- Unexplained weight loss
- Any symptom that concerns you, has no explanation and lasts more than 2 weeks e.g. cough

6. Booking a PCFU appointment

Once the patient has phoned the helpline with concerning symptoms, they will be fast tracked and booked into the next available Consultant led Gynaecology Oncology clinic.

7. GP Communication

On discharging a patient on to the PCFU pathway it is important that the GP is informed via a clinical letter written by the patient's named consultant (Bluespier). The GP should also receive a copy of the end of treatment summary.

Clinical protocols

Endometrial cancer guidance

***ROR-** risk of recurrence

BGCS guidelines April 2020

Endometrial Cancer	**PIFU/PCFU**	**Clinic-based Follow- up**	**Telephone Follow up +/- blood test**
Low risk *(<10% ROR)* Stage 1 Grade 1-2	Offer from end of treatment (after HNA at 3 months) and end of treatment summary	If patient declines PIFU/ PCFU (For maximum of 2 years from the end of treatment	If patient declines PIFU/ PCFU (For maximum of 2 years from the end of treatment
Intermediate risk *(10-20% ROR)* Grade 1-2 after radiotherapy	Offer from end of treatment (after HNA) and end of treatment summary or after 2 years for all	Can be offered if patient declines PIFU/PCFU for 2 years from the end of treatment	Can be offered if patient declined PIFU/PCFU from end of treatment
High-Intermediate risk *(>20% ROR)* - Stage 1-2 (>50% myometrial invasion) - Stage 1a Grade 3 tumours (<50% myometrial invasion)	Offer from 2 years from end of treatment in place of telephone follow up or clinic follow up	For 5 years (either telephone follow up or clinic follow up	For 5 years (either telephone follow up or clinic follow up
High-grade serous/ Clear cell cancers Stage 1b Grade 3	Not for PIFU/PCFU unless discussed and agreed on patient basis by MDT	For 5 years clinic follow up	For 5 years clinic follow up (2 years minimum) and then telephone follow up for remaining 3 years
Stage 4 Palliative	End of treatment Discharge to PIFU/ PCFU from Combined Clinic (MDT discussion) to PIFU	As required by individual.	As required by the individual

Cervical cancer guidance

***ROR-** risk of recurrence

BGCS guidelines April 2020

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

Ovarian cancer guidance

***ROR-** risk of recurrence

BGCS guidelines April 2020

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

3.4 Vulvar Cancer

***ROR-** risk of recurrence

BGCS guidelines April 2020

Vulvar Cancer	**PIFU**	**Clinic-based Follow- up**	**Telephone follow up +/- blood test**
	Not suitable	Follow up including clinical examination for at least 5 years from the end of treatment	Not suitable

Appendix 1

PCFU Patient information leaflet.do

Appendix 2

Alert Card

Gynaecological Cancer

Patient Centred Follow Up

Clinical Nurse Specialist Helpline

Direct Telephone Number 01905 733257

What are the signs & symptoms I need to look out for and report?

- Sudden start of vaginal bleeding or vaginal discharge (offensive in smell or an unusual colour)
- Abdominal, pelvic or back discomfort that does not go away
- Abdominal swelling that steadily gets worse
- Change in bowel or bladder habits
- Unexplained weight loss
- Any symptom that concerns you, has no explanation and lasts more than 2 weeks e.g. cough

References

1. Int J Gynecol Cancer: first published as 10.1136/ijgc-2019-001176 on 19 April 2020. Downloaded from https://ijgc.bmj.com/ on April 21, 2020 at European Society of Gynaecological Oncology.

2. Newton C, et al. Int J Gynecol Cancer 2020;0:1–6. doi:10.1136/ijgc-2019-001176

Acknowledgements

Gloucester Hospital NHS Trust, Gynaecology Cancer MDT, follow up algorithms.