Greater Manchester
Cancer Alliance

Personalised Stratified Follow up and Patient Initiated Follow Up for Gynaecological Cancers

Document Control

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Signed off by	**GM Cancer Gynaecology Pathway Board 2021** **For review November 2023**
Date	**27/10/2023**
Version Number	**1.1**
Date for Review	**November 2025**

Version number	Date	Revision Author	Status	Revision Made
0.7	2021	Pathway Board	Final	Final version signed off
0.8	23/10/2023	A Webber	Draft	Transferred onto new GM Template and small revisions
0.9	27/10/2023	A Webber	Draft	Revised after initial discussions
1.1	02/11/2023	A Webber	Draft	Typo – changed colorectal to gynaecology on document control

With special thanks to Claire Newton, Consultant Gynaecological Oncologist, UH Bristol and Weston foundation NHS Trust on whose protocol this one is based.

1. Purpose

This document provides local guidance for Personalised Stratified Follow Up (PSFU) and Patient Initiated Follow Up (PIFU) within the Greater Manchester Gynae-oncology cancer pathway.

It applies to all Greater Manchester local units and specialist centres involved in the treatment of patients with a gynaecological cancer. This model of care is aligned with the NHS Long Term Plan for Cancer, British Gynaecological Cancer Society (BGCS) recommendations, NHSE Personalised Care for Cancer Initiative. Phase 3 COVID Recovery Planning, the GM Cancer Plan and NHS 21/22 22/23 and 23/24 priorities and operational planning guidance.

2. Introduction

The overall aim of PSFU is to improve patient experience and outcomes with tailored aftercare and supported self-management. It is intended to meet the wider needs of a cancer survivor than is possible by routine clinic follow up alone. It reduces the frequency of hospital-based outpatient appointments but must be supported with rapid access to clinical review if symptoms of recurrence are reported.

3. What is PSFU?

PSFU describes the delivery of personalised ongoing care to cancer patients that supports them towards self-management based on individual risk stratification, needs and preferences rather than the traditional clinic based follow up.

In order to self-care effectively, patients must have good knowledge, skills and confidence about their condition.

. This is supported by the following aspects of PSFU:

- End of Treatment Summaries (provides information/knowledge) (Current versions available on the GM website)
- Supported self management (access to CNS, support groups, written information)
- Shared decision making (Patient involvement in treatment and follow up decisions)
- Health and wellbeing information support related to specific patient needs throughout the pathway
- Personalised care and support planning
- Cancer Care Review within primary care
- PIFU, if appropriate.

Patients do not receive routine follow-up appointments (hospital, telephone or with a general practitioner), but instead are empowered to call the gynaecological oncology team directly via their named Gynaecology Cancer Clinical Nurse Specialist (CNS). As the Gynae Cancer CNS has specialist cancer knowledge, they are able to either fast track women back to their specialist teams for concerns about recurrence or treatment side effects (ideally should be seen within 7 days) or to signpost /refer women to the appropriate support services for other issues.

4. What is PIFU?

PIFU is simply one aspect of PSFU and is suitable for many patients following treatment for gynaecological cancer (see section 5). In PIFU, patients do not receive routine follow-up appointments (hospital, telephone or with a general practitioner), but instead are empowered to call the gynaecological oncology team directly via their named Gynaecology Cancer Clinical Nurse Specialist (CNS). As the Gynae Cancer CNS has specialist cancer knowledge, they can either fast track women back to their specialist teams for concerns about recurrence or treatment side effects (ideally should be seen within 7 days) or to signpost /refer women to the appropriate support services for other issues.

5. Eligibility Criteria

PIFU should be offered on a case-by-case basis, ensuring there are no existing unmet needs and according to the patient's cancer type.

PIFU follow up is **not appropriate** for some gynaecological cancers as listed here:

Endometrial

- Stage 2-3
- Stage 4

Cervical

- Stage 1a1: Lletz
- Stage 1b2
- >Stage 1b2
- Fertility preservation surgery

Epithelial Ovarian

- Fertility preservation surgery
- Stage 1C-4

Other Cancers

- Vulval Cancer
- Vaginal Cancer

Neither is it appropriate if patients have significant side effects from their cancer treatment impairing their quality of life. Women that require active management of side effects should be seen in clinic by the appropriate health professionals such as gynaecologist, gastroenterologist, urologist, or psychologist.

Suitability is determined by the patient and the treating team and should be assessed using the following criteria.

- Completed primary treatment for a gynaecological malignancy and clinically well
- No physical, cognitive or emotional issues affecting their ability to self-manage.

- Have capacity to consent to PIFU.
- Able to communicate their concerns.
- Are willing and able to access healthcare.
- Not on active or maintenance treatment.
- No diagnosed recurrent disease.
- No significant treatment related side- effects.
- Not on a clinical trial.
- Do not have a rare tumour.

Trusts will also complete an Equalities Impact Assessment for PSFU and PIFU which will include specific cohorts of patients with protected characteristics that should be included with reasonable adjustments made, or excluded. The EIA should be read alongside this protocol.

6. PIFU by tumour groups and schedule

The BGCS recommendations for PIFU are based on risk of recurrence.

Low Risk – Risk of recurrence <10%

Intermediate – Risk of recurrence 10-20%

High Risk – Risk of recurrence >20%

Endometrial Cancers		PIFU to be considered	Follow up if PIFU not suitable
Low Risk	**Stage 1a endometrioid adenocarcinoma, G1-2, no LVSI**	Yes Offer from end of treatment review/ 3 month HNA	Hospital based clinic follow-up for 5 years
Intermediate Risk	**Stage 1b endometrioid adenocarcinoma, G1-2, no LVSI**	Yes Offer from end of treatment review/ 3 month HNA or After 2 years clinic follow up	Hospital based clinic follow-up for 5 years
	Stage 1a endometrioid grade1-2, positive LVSI (LND negative)	Yes Offer after 2 years clinic follow up	Continue hospital-based clinic follow-up for a total of 5 years
High-intermediate risk	**Stage 1b endometrioid adenocarcinoma, G1-2, positive LVSI**	Yes Offer after 2 years clinic follow up	Continue hospital-based clinic follow-up for a total of 5 years
	Stage 1a G3 endometrioid	Yes	Continue hospital-based clinic follow-up for a total of 5 years

		Offer after 2 years clinic follow up	
High risk	**Non endometrioid cancers (serous/clear cell)**	Yes Offer after 2 years clinic follow up	Continue hospital-based clinic follow-up for a total of 5 years
	Stage 1b, G3 endometrioid	Yes Offer after 2 years clinic follow up	Continue hospital-based clinic follow-up for a total of 5 years
	Stage 2-3	No	Hospital-based clinic follow-up
	Stage 4	No	Hospital-based clinic follow-up

Cervical Cancers		**PIFU to be considered**	**Follow up if PIFU not suitable**
Low Risk	**Stage 1a1: Lletz**	No	As per BSCCP guidance
	Stage1a1	Yes Offer after 2 years clinic follow up	Continue hospital-based clinic follow-up for a total of 5 years
	Stage 1a2	Yes Offer after 2 years clinic follow up	Continue hospital-based clinic follow-up for a total of 5 years
	Stage 1a3	Yes Offer after 2 years clinic follow up	Continue hospital-based clinic follow-up for a total of 5 years
Intermediate Risk	**Stage 1b2**	No	Hospital based clinic follow-up for 5 years
High Risk	**>Stage 1b2**	No	Hospital based clinic follow-up for 5 years
	Fertility preservation surgery	No	Individualised follow up

Epithelial Ovarian Cancers		**PIFU to be considered**	**Follow up if PIFU not suitable**
Low Risk	**Stage 1a/b fully staged (excluding fertility sparing surgery)**	Yes Offer from end of treatment review/ 3 month HNA	Hospital based clinic follow-up for 5 years
	Fertility preservation surgery	No	Hospital based clinic follow-up for 5 years
	Stage 1C-4	No	Hospital based clinic follow-up for 5 years

Other Cancers		PIFU to be considered	Follow up if PIFU not suitable
	Vulval cancer	No	Hospital based clinic follow-up for 5 years
	Vaginal cancer	No	Hospital based clinic follow-up for 5 years

7. PIFU process

The concept of PIFU should be introduced prior to surgical discharge or during the chemotherapy/radiotherapy treatment. It may be introduced in the diagnostic phase, if appropriate, but care should be taken to avoid information overload at this stage. The clinician and CNS should discuss PIFU, if appropriate, at both the routine post treatment clinic review and the 3-month end of treatment Holistic Needs Assessment (HNA). It should be carefully explained that there is a lack of evidence of benefit from regular follow up visits in terms of earlier pick up of treatable recurrence. The rationale of self-management should also be discussed so that patients are clear that they are expected to contact the CNS with any concerns so that appropriate and timely follow up can be actioned whenever it is needed.

Suitability for PIFU should be recorded at post-operative or treatment planning SMDT. To ensure women are fully informed about their PIFU decision, they should be given specific written information about PSFU/PIFU. All women should be given time to decide if they need to reflect on the PIFU information and reassured that they can convert to traditional clinic follow up at any time if they so wish.

Women who opt for PIFU should be reassured that they will receive the following to support them:

- Tumour specific written information (usually given at diagnosis)
- End of Treatment Summary (EOT) (**latest version on GM website**) should be given/sent after treatment is completed. The EOT should be sent to the patient and GP and includes details of the treatment, treatment outcome, symptoms of side effects or recurrence and contact details for the CNS.
- End of Treatment personalised care and support plan.
- PIFU written information (**Appendix 1**)
- Contact details for the Gynae Cancer CNS
- Reminders/ appointments for routine follow up tests, if appropriate.
- Annual letter to them and GP to check happy to continue with PIFU and that no changes in circumstances that contraindicates PIFU (eg dementia) (**Appendix 2**).
- A discharge letter at the end of the traditional follow up period for their cancer type.

8. PIFU governance

It is the responsibility of the clinician and CNS to identify and offer PIFU to appropriate women.

If women contact the CNS with symptoms of possible recurrence, they must be offered a clinical assessment within 7 days.

Appropriate cross cover arrangements for the CNS must be in place to ensure patient contacts are not unduly delayed due to planned/unplanned leave.

It is the responsibility of the CNS to enrol patients who agree to PIFU onto a secure digital system.

It is the responsibility of the Provider’s Gynaecology Cancer Clinical Lead that the system is installed and fit for purpose.

In-built alerts for routine tests/letters will be installed in the system with agreed alerts to the appropriate clinicians and CNS.

It is the responsibility of the recipient of the alerts to action and follow up the alerts.

The database must be updated with all contacts from the patient, all test results and outcomes. This will usually be inputted by the CNS or Cancer Care Coordinator. Additional clinic reviews by the Gynaecologist should be updated by the clinician or CNS.

Updating database, routine test requests and annual letters can be delegated to appropriately trained members of the Gynae-oncology team.

9. Ongoing audit

There will be an ongoing audit of patients on a gynae-oncology PIFU pathway.

Patient’s Quality of Life will be monitored by the national Quality of Life Metric with results for gynae-oncology patients regularly reviewed by the Gynae-Oncology Pathway Board when they are available.

Further audits will be undertaken to monitor (again overseen by the Gynae-Oncology Pathway Board):

- Recurrence rates /survival outcomes.
- Number of patients participating PIFU.
- Adherence to PFSU criteria.
- Number of contacts/emergency appointments with symptoms suggestive of recurrence with no recurrence found.

10. References

British Gynaecological Cancer Society recommendations and guidance on patient-initiated follow-up (PIFU). Newton C, Nordin A, Rolland P, et al. Int J Gynecol Cancer (19.04.20) doi:10.1136/ijgc-2019-001176.

NHS Long Term Plan, 07.01.19 (updated August 2019).

NHS England and NHS Improvement, Implementing Personalised Stratified Follow Up Pathways, March 2020.

Appendix 1. Patient information leaflet

Your Patient Initiated follow up (PIFU) information for Endometrial, Cervical and Ovarian Cancer

Patient information leaflet

Introduction

The PIFU service has been specifically designed to support you when you have completed your treatment. It is a type of follow-up where you, the patient, are in control. It means that your normal routine will not be disrupted by regular hospital appointments. Instead, you can quickly gain access to your clinical specialist team and hospital when you need to. It is based on evidence showing that symptoms and concerns are addressed more quickly if patients report them as and when they occur, rather than waiting for a routine appointment.

End of Treatment Review

Following your treatment, you will be offered an end of treatment review appointment with your clinical specialist team. This will help you to prepare for the next stage of your care, where you are in control with the support of your clinical team.

At this appointment you will be given an end of treatment summary that will include:

- A summary of your diagnosis and treatment.
- Information on any future appointments and tests.
- Information about the symptoms and side effects that you need to be aware of, and who to contact should you experience them.
- Advice on how to keep yourself well.
- Information on the services available to support you in moving forward following your treatment.
- Information on how to contact your clinical specialist team.

A copy of your end of treatment summary will also be sent to your GP.

Patient Initiated Follow-Up

You can contact your clinical nurse specialist team when you need to to discuss any worries or concerns you may have. Your Cancer Care Coordinator also works within the nurse specialist team and has lots of information on resources available to support you - they are often a good first point of contact.

The aim of the service is to provide helpful advice and allow you to have rapid access back to your clinical specialist team, as required.

You should phone us if:

- You are having ongoing problems following your treatment that you need help with.

- You have any new symptoms that you are concerned about.
- You would like to talk to someone about issues relating to your health and wellbeing.

What will happen when I ring my clinical specialist team?

Your clinical specialist team may recommend one of the following:

- That you make an appointment to see your GP
- Give you reassurance that no further action is needed
- Or they may recommend a clinic appointment at the hospital – if this is needed, you will be offered an appointment no later than 2 two weeks from contacting the team.

If you require immediate support at the weekend or bank holidays, please contact your GP out of hours service or NHS 111 for advice. If you feel you need more immediate attention, please attend your local Accident and Emergency Department, and present your treatment summary to the local acute oncology team who can work with clinical teams to support you.

When should I see my GP?

It is important to remember that you will still get coughs, colds, aches and pains just like anybody else. If you see your GP for any other issues and they are concerned they can contact your clinical nurse specialist team who can arrange for you to be seen in hospital.

Continuing to support you

If you change your address, please let your clinical nurse specialist team know so that we can continue to contact you for the first five years after your diagnosis. After this point you will be discharged to your GP.

Finally

If you are worried about something to do with your cancer diagnosis, or the treatment that you have had for it, please contact your clinical nurse specialist team. They would rather see you with something that turns out to be nothing, than for you to be at home worrying. They are there to help you, so please call if you have any questions or concerns.

Further information and useful contacts

Cancer Research UK

Helpline: 08088004040

Website: www.cancerresearchuk.org

Macmillan Cancer Support

Tel: 08088080000

Website: www.macmillan.org.uk

Citizens Advice Bureau

Website: www.citizensadvice.org.uk

Appendix 2. Annual check In letter

Patient Name

Patient Address

Date of Birth: 00/00/0000

Hospital Name

Hospital Address

Hospital No: 01234567

NHS No: 999 999 9999

Dear

Annual Patient Initiated Follow Up Check-in

I hope you are staying well on your Patient Initiated Follow Up.

We will send you this letter yearly while you are on this type of follow-up to check that you are staying well, or, if you are having any problems or changes in circumstances, to remind you that your team are there to support you and can be contacted at any time if you have any queries or concerns.

Also, if you do not feel fully supported on this type of follow-up, you can choose to return to follow-up carried out by out-patient appointments. Please contact your team should you wish to do this.

Key Contact Numbers:

Clinical Nurse Specialists	**Name:** **Contact Number:**
Cancer Care Coordinator	**Name:** **Contact Number:**

Also, as a reminder, please see below some key information:

Symptoms of possible recurrence that require investigation:

It is important to raise any concerns you have or any new symptoms you are experiencing with your Clinical Nurse Team as soon as possible. New symptoms do not automatically mean that your cancer has returned but that further assessment may be needed. **Please contact your Clinical Nurse Specialist Team if you experience any of the following:**

- Vaginal bleeding and/or discharge
- Bleeding after sex

- Persistent abdominal bloating that last longer than 4 weeks
- Persistent pelvic or abdominal discomfort that lasts longer than 4 weeks.
- Leg swelling
- Unexplained weight loss

Additional information relating to lifestyle and support needs:

A number of lifestyle choices can affect your ongoing health and wellbeing. These can help you regain or build physical strength, reduce severity of side effects and reduce the risk of developing secondary cancers or other health issues. This is also an important time for you to regain or feel more in control of your health and wellbeing, often ‘lost’ when you are diagnosed with cancer.

Lifestyle factors that can help to reduce the risk of cancer returning are listed below. For support on any of these points, please contact your Clinical Nurse Specialist team.

- **Taking medication as advised**
- **Regular physical activity**
- **Maintaining a healthy weight**
- **Reducing alcohol intake**
- **Stopping smoking**

Managing your wellbeing: Looking after yourself in good times and bad

We can all struggle on a day-to-day basis. Dealing with a diagnosis of cancer and undergoing treatments can be particularly challenging and it may add an additional level of complexity in looking after yourself when you are not feeling your best. You may notice that you are more worried and stressed than usual, or you may feel sluggish and low. Adjusting and adapting to everything you have been through can take time, and sometimes it needs a bit of extra support and effort to figure out how to be okay when life is proving challenging. There is help available if you need it.

Annual Check in letter completed by:	
Copy sent to GP:	