PATIENT STRATIFIED FOLLOW UP AND PATIENT INITIATED FOLLOW UP FOR GYNAECOLOGICAL CANCERS

Document Control

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Signed off by	**GM Cancer Gynae-Oncology Pathway Board**
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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 GM Gynae-oncology cancer pathway.

It applies to all GMEC local units and specialist centres involved in the treatment of women with a gynaecological cancer. This model of care is based on British Gynaecological Cancer Society (BGCS) recommendations and is aligned with the NHS Long Term Plan for Cancer, NHSE Personalised Care for Cancer Initiative. Phase 3 COVID Recovery Planning, the GM Cancer Plan and **NHS 2021/22 and 22/23 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, women 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) (**Appendix 1**)
- 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.

4. What is PIFU?

PIFU is simply one aspect of PSFU and is suitable for many patients following treatment for gynaecological cancer (see section 6). 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 are able to either fast track women back to their specialist teams for concerns about recurrence or treatment side effects (**to be seen within 14 days**) or to signpost /refer women to the appropriate support services for other issues.

5. Eligibility for PIFU

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 is not appropriate for cervical cancers requiring follow up smears, vulval or vaginal cancers. 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.

6. Eligibility 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.

7. PIFU by Tumour Groups

The BGCS recommendations for PIFU are based on risk of recurrence. This is stratified into low, intermediate, high risk which denote risk of recurrence in <10%, 10-20% and >20% respectively.

Endometrial Cancers	PIFU	Clinic Follow-up
Low risk • **Stage 1a endometrioid adenocarcinoma, G1-2, no LVSI**	Offer from end of treatment review/3-month HNA	If PIFU not appropriate, hospital based clinic follow-up for 5 years
Intermediate risk • **Stage 1b endometrioid adenocarcinoma, G1-2, no LVSI** • **Stage 1a endometrioid grade1-2, positive LVSI (LND negative)**	Offer from end of treatment/3-month HNA or after 2 years clinic follow up.	If PIFU not appropriate, clinic follow-up for 5 years.
High-intermediate risk • **Stage 1b endometrioid adenocarcinoma, G1-2, positive LVSI** • **Stage 1a, G3 endometrioid**	Offer after 2 years clinic follow up.	If PIFU not appropriate, then continue clinic follow-up for total 5 years.
High risk • **Non endometrioid cancers (serous/clear cell)** • **Stage 1b, G3 endometrioid**	Offer after 2 years clinic follow up.	If PIFU not appropriate, then continue clinic follow-up for total 5 years.
Stage 2-3	Not suitable	Clinic based follow up
Stage 4	Not suitable	Clinic based follow up.

Cervical Cancer	PIFU	Clinic Follow-up
Low risk • **Stage 1a1: Lletz**	Not suitable	As per BSCCP guidance
Low risk • **Stage 1a1:** • **Stage 1a2:** • **Stage 1b1:**	Offer after 2 years clinic follow up.	5 years clinic based follow up
Intermediate risk • **Stage 1b2**	Not suitable	5 years clinic based follow up
High risk • **>Stage 1b2**	Not suitable	5 years clinic based follow up
Fertility preservation surgery	Not suitable	individualised follow up

Epithelial Ovarian Cancer	PIFU	Clinic Follow-up
Low risk • **Stage 1a/b fully staged (excluding fertility sparing surgery)**	Offer from End of Treatment/ 3-month HNA	If PIFU not appropriate, clinic follow-up 5 years.
Fertility preservation surgery	Not suitable	5 years clinic based follow up
Stage 1C-4	Not suitable	5 years clinic based follow up

Other Cancers	PIFU	Clinic Follow-up
Vulval Cancer	Not appropriate	5 years clinic based follow up
Vaginal Cancer	Not appropriate	5 years clinic based follow up

8. 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) (**Appendix 1**) 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 2**)
- 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 3**).
- A discharge letter at the end of the traditional follow up period for their cancer type.

9. 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 14 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 on the InfoFlex database/ equivalent system.

It is the responsibility of the Provider's Gynaecology Cancer Clinical Lead that the InfoFlex or equivalent database is installed and fit for purpose.

In-built alerts for routine tests/letters will be installed in the Infoflex system (or equivalent 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.

10. 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

11. 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: Endometrial Treatment Summary

For GP use only: please code this letter as cancer treatment completed:

Snomed code 413 37006	Cancer hospital treatment completed (situation)	
8BCF.00	Read	Cancer hospital treatment completed

GM Cancer Endometrial Cancer Treatment Summary Template

This Treatment Summary is designed specifically for the following endometrial cancers:

- **ENDOMETRIAL G1-2, STAGE 1A NO LVSI, NO XRT**
- **ENDOMETRIAL Stage 1b, G1-2, no LVSI. May have TAHBSO +/- brachy**
- **ENDOMETRIAL G1-2, STAGE 1B NO LVSI WITH BRACHY**

Please delete this title and box after reading these instructions.

Remove all wording that does not apply to a particular patient in order to personalise it to the individual.

If you need to localise this treatment summary, eg job titles do not match those used in your Trust or adding your Trust logo, please do so, but please retain all other information.

Remember to ensure sections don't overrun onto the next page or titles separate from the body of the text before sending.

Patient Name
Patient Address

Hospital Name
Hospital Address

Date of Birth: 00/00/0000
Hospital No: 01234567
NHS No: 999 999 9999

Dear ***[INSERT PATIENT NAME]***

Please find below the summary of your diagnosis and treatment for endometrial cancer, possible effects of treatment and your ongoing management plan that we discussed. A copy of this has also been sent to your GP. This plan is specific to your needs and has been designed to increase your knowledge and wellbeing as you move forward in your cancer care.

Please remember that if you do feel anxious or would like further advice or to talk through a concern or symptom at any time, you are welcome to contact your Clinical Nurse Specialist Team. They are there to support you as and when you need. Ongoing support and advice is also available from your Cancer Care Coordinator who works within the Cancer Nurse Specialist Team. They have a wealth of knowledge about resources and support that are available to you and are often a good first point of contact.

Key Contact Numbers:

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

	Contact Number:

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

Diagnosis and Treatment to Date:

Diagnosis:	*Please give full details*	**Date of Diagnosis**:	
Histology:			
Treatment aim:			
Summary of Treatment and relevant dates: *Please be specific and give full details, avoiding jargon.*			

Health and Wellbeing Information and Support:

Access to Health and Wellbeing Information and Support is part of your care.

You have been referred to the following services:
(Please populate with services referred to)

Below is a list of services that you may be able to access for support in your area. **Please contact your Clinical Nurse Specialist at any time if you feel your needs have changed and you would like referring to a service for further support.**

- Benefits Advice Service
- Bowel / Bladder Continence Service
- Counselling
- Complementary Therapist
- Dietitian
- District Nurse
- Macmillan Cancer Information & Support Centre
- Occupational Therapist
- Physical Activity
- Psychologist
- Physiotherapist
- Changes in sexual function
- Social Worker
- Support Group
- Other:

Further Treatment and Management (ongoing tests and appointments):

[DELETE AS APPROPRIATE]

Low Risk Stage 1a endometrioid adenocarcinoma, G1-2, no LVSI
Your Clinical Nurse Specialist Team will be in contact in 3 months for a telephone review appointment.

You will remain under the care of the Clinical Nurse Specialist Team for the next 5 years. During this time, your Clinical Team will be available to support you as and when you need. At any point, should you have any worries or concerns or would like to discuss a new symptom or side effect of treatment, please contact your Clinical Nurse Specialist Team directly without delay.

Intermediate Risk Stage 1b endometrioid adenocarcinoma, G1-2, no LVSI
Your Clinical Nurse Specialist Team will be in contact in 3 months for a telephone review appointment.

You will remain under the care of the Clinical Nurse Specialist Team for the next 5 years. During this time, your Clinical Team will be available to support you as and when you need. At any point, should you have any worries or concerns or would like to discuss a new symptom or side effect of treatment, please contact your Clinical Nurse Specialist Team directly without delay.
Or
You will be required to attend a clinic appointment every 4 months for the next 2 years.

After 2 years, you will no longer have regular clinical appointments scheduled. Instead, your Clinical Nurse Specialist Team will be available to support you as and when you need. At any point, should you have any worries or concerns or would like to discuss a new symptom or side effect of treatment, please contact your Clinical Nurse Specialist Team directly without delay.

Things for you to do:

- If you do not receive a date for your follow-up test as per the above schedule, or if your tests are cancelled and rebooked, please contact your Cancer Care Coordinator to discuss.

- Please contact your GP to schedule an appointment for a Cancer Care Review. This should take place at 3 months and 12 months after your cancer diagnosis.

- We recommend you have your annual flu jab

Possible Side Effects from the treatment(s) you have had

Some side effects can improve quickly, however some, such as fatigue, may take longer to improve. **If you are struggling to cope with side effects, or if the side effects are getting worse rather than better, please contact your Clinical Nurse Specialist Team for advice.**

[DELETE AS APPROPRIATE]

Possible side-effects from surgery

- Lower abdominal pain (post-operative adhesions)
- Weakening of abdominal scar (hernia)
- Premature menopause
- Fluid filled cysts (lymphocysts) (if lymph nodes has been surgically removed)
- Swelling/fluid build-up in one or both legs (lymphoedema) (if lymph nodes has been surgically removed)
- Weakening of bones (Osteoporosis) (if premenopausal pre op)
- Sexual concerns/dysfunction
- Change in bladder/bowel habit
- Pain with sex
- Emotional concerns and worries

Possible side-effects from radiotherapy

- Fatigue
- Diarrhoea
- Problems urinating

- Vaginal scarring or dryness

Although lymphoedema is not a common side effect, the risk is higher if you have had surgery to remove the lymph nodes as well as radiotherapy. There are steps you can take to reduce the risk of developing lymphoedema and your Clinical Nurse Specialist can explain these and provide you with further 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.

Other useful numbers:

Other ***[INSERT DETAILS]***	***[INSERT CONTACT DETAILS]***
Other ***[INSERT DETAILS]***	***[INSERT CONTACT DETAILS]***
Other ***[INSERT DETAILS]***	***[INSERT CONTACT DETAILS]***

Treatment Summary Completed by:	
Copy sent to GP:	□
Copy sent to Consultant:	□
Copy sent to other Health Care Professional(s):	**[INSERT DETAILS]**

ADDITIONAL NOTES FOR GP

For GP use only: please code this letter as cancer treatment completed:

Snomed code 413737006	Cancer hospital treatment completed (situation)	
8BCF.00	Read	Cancer hospital treatment completed

Personalised Care and Support Plan □ (attached)	
Health and Wellbeing Information and Support given	**See referral advice given on services available**
Prescription Charge exemption certificate □	**Free prescription reminder □**
Advice given to apply for Personal Independence Payment (PIP)	Yes/No/Not applicable

Will *[INSERT PATIENT NAME]* be self-managing?	**Yes / No [DELETE AS APPROPRIATE]** ***[IF NO PLEASE STATE REASON]***
Advise entry onto primary care palliative or supportive care register?	Yes/No/Not applicable
DS1500 application completed?	Yes/No/Not applicable
Required GP actions (e.g. ongoing medications/ osteoporosis screening) Cancer Care Review Follow instructions as per oncology treatment summary on completion of adjuvant treatments. ***All treatment summaries are subject to review in light of evidence based changes to clinical protocols and treatment toxicity.*** ***Additional resources and information for primary care staff are available through www.gatewayc.org.uk***	

Patient-initiated follow-up after treatment for endometrial cancer

Patient Information

This information is for patients on our patient-initiated follow-up service.

The patient-initiated follow-up (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 in order 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
- They may reassure you 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 3: Annual Check-in Letter

LETTER TO BE ADDED TO INFOFLEX AND SENT OUT ANNUALLY

Patient Name
Patient Address

Hospital Name
Hospital Address

Date of Birth: 00/00/0000
Hospital No: 01234567
NHS No: 999 999 9999

Dear ***[INSERT PATIENT NAME]***

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 Specialist	**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**

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